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UNRESTRICTED

James Gray
Dissertation
July 1996

**Psychological well-being and coping in the partners of gay
men with HIV-related disease.**

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Psychology.

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Abstract

This study explored psychological distress and well-being in the (HIV negative) partners of gay men with HIV infection and related illness. The role of coping as a moderating variable was investigated. Other moderating variables known to influence level of distress for carers (such as social support, quality of the relationship and life events) were also examined.

35 partners made up the final sample. Clinically significant levels of distress were found. Several coping strategies were significantly ($p < .05$) correlated with psychological distress and well-being. These strategies were: acceptance, behavioural disengagement, mental disengagement, focusing on emotions, and suppression of competing activities. Regression analysis showed that significant amounts of the variance in psychological distress were explained by some of these strategies. Other factors that were also important predictors in the regression equations included: the overall health of the patients, the satisfaction with social support, other stressful life events, and previous experience of HIV related bereavement. Clinical implications, methodological issues and avenues for future research are discussed.

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1.0 INTRODUCTION

There is increasing interest in those people affected by HIV (human immunodeficiency virus), as well as those infected by the virus. A new group of informal carers, partners of gay men with HIV, has appeared that contrasts strongly with traditional carer groups. Little is known about the challenges they are facing and yet there will be an increasing reliance on these carers as the epidemic progresses and statutory resources are further stretched. The current study was initiated in order to increase knowledge of the psychological impact of being a partner of someone with HIV infection and to investigate how coping strategy and other moderating variables influence this impact.

In the introduction, the relevant literature is reviewed. The background medical information and the known psycho-social impact of HIV on infected and affected people is presented. Then brief review is made of the literature on stress, coping, social support and other moderating factors. The review focuses on studies specific to chronic illness and HIV, in view of the vast body of work on each of these topics. Finally the specific aims and hypotheses of the current study are outlined.

1.1 Background medical information:

History

AIDS (Acquired Immune Deficiency Syndrome) is a progressive, immunological disorder first recognised in the United States in 1981 (Centers

for disease control, 1981). A cluster of two previously extremely rare medical conditions, pneumocystis carinii pneumonia (PCP), and the cancer Kaposi's sarcoma (KS), appeared in a group of gay men. Their immune systems were found to be weakened. Initially a range of explanations, including lifestyle, was suggested. It was not until 1983 that the virus responsible (subsequently named HIV) was isolated and a test for the presence of antibodies to it developed. People testing positive for these antibodies are termed 'HIV positive' and those testing negative, 'HIV negative'.

Transmission

HIV can be transmitted by: the exchange of infected body fluids during sexual intercourse; by infected blood, tissue or organ products in medical procedures; from sharing needles in drug abuse; or from mother to child across the placenta or possibly through breast milk. Due to this pattern of transmission several members of a social network can be infected and face the possibility of AIDS.

Incidence

The virus has spread extensively throughout the world, although there have been different patterns of infection. In Western countries such as the US the vast majority of people infected so far have belonged to groups including gay men, intravenous drug users and haemophiliacs. AIDS has become the leading cause of death amongst adults in several US cities (Schoub, 1994). In Africa the dominant mode of transmission has been heterosexual sex (e.g.

Nzioka, 1994). AIDS has become a pandemic (affecting every continent) and there are estimated to be more than 14 million people worldwide infected with HIV (WHO, 1994).

In the UK there have been over 11,000 AIDS cases (Communicable disease report, 1995) with over 24,000 known to be infected with the virus ('HIV-positive'). Sixty-one per cent of infections are thought to have been due to sex between men, eighteen per cent from sex between men and women, eleven per cent through injecting drug use and six per cent from blood or tissue products (Communicable disease report, 1995).

Medical effects

HIV attacks and gradually destroys several cells in the body, including an essential part of the immune system, the lymphocytes known as 'T-helper' cells. The progression of infection and immuno-suppression takes place over several years and can be crudely measured by the 'T-cell' or 'CD4' count. Rates vary widely and some people appear to be naturally immune to the virus. When the functioning of the immune system drops below a certain level the individual becomes susceptible to a variety of opportunistic infections and cancers. These include: lung infections such as PCP; gastro-intestinal disorders such as cryptosporidiosis; infections of the brain and central nervous system such as Toxoplasmosis; other viral infections such as Cytomegalovirus (which can lead to blindness); and cancers such as Kaposi's Sarcoma (see e.g. Schoub, 1994). In addition the virus can have a direct

action on the brain and cause a form of sub-cortical dementia, HIV encephalopathy (Navia, Jordan and Price, 1986). AIDS is diagnosed when a person with HIV infection contracts one of the conditions listed above (or a variety of other illnesses), indicating a compromised immune system.

There is huge variation in each individual's medical response to HIV infection. It is impossible to know when and in what way a person infected with HIV will become ill. AIDS has been described as an emotional rollercoaster ride (Raveis and Siegel, 1991). The proportion of infected people who will eventually die from one of the many complications is unknown. A number of anti-viral treatments have been developed such as the drug zidovudine (AZT) but this has limited efficacy and there can be serious side-effects. More effective have been drug treatments and prophylaxis for opportunistic infections such as PCP.

Societal response

AIDS has uncovered a large amount of public ignorance, hostility and 'moral panic' (e.g. see George, 1989, King, 1990). Sontag (1990) describes how society's response to HIV and AIDS mirrors earlier responses to 'dreaded diseases' such as cancer, syphilis, leprosy and plague. Sontag argues that with HIV you have elements of all such responses (stigma and rejection) due to its sexually transmitted nature and its disfiguring and disabling effects.

There are thus many reasons why HIV can be associated with considerable psychological distress, both for people 'infected', and people 'affected' by the virus such as partners, family and friends.

1.2 Psychological impact of HIV on infected individuals:

Testing for the virus

High levels of psychological distress have been shown immediately prior to testing for HIV (Perry, Jacobsberg, Fishman, Frances, Bobo, and Jacobsberg, 1990). For people who received a negative result there was immediate and sustained relief and even those who tested positive, showed a decrease in distress (Perry, Jacobsberg, Fishman, Weiler, Gold and Francis, 1990). This may have been due to the reduction in uncertainty or a reflection of the post-test counselling that is routinely offered (McCann, 1992). From clinical experience George (1989) outlines the most commonly observed reactions to an HIV diagnosis as being: shock, relief, anger, guilt, decreased self esteem, loss of identity, loss of a sense of security, loss of personal control, fear, sadness and depressed mood, obsessions and compulsions, and positive adjustment.

Persistent psychological distress

Reports of rates of persistent psychological distress in people with HIV infection vary widely depending on the sample selected. King (1989) found a rate of 31 per cent 'significant psychiatric problems' in 192 consecutive clinic attenders in London. These were largely anxiety states, neurotic depression,

and prolonged adjustment disorders. He claimed that this rate was very similar to other people presenting with serious physical disorders (King 1993). Other researchers have found far higher rates of disorder e.g. 83 per cent for mood disorder (Perry and Tross, 1984), but their methodology was less stringent (using medical notes) and their sample were inpatients in New York at an early stage in the epidemic. Suicidal ideation was found to be high soon after testing HIV positive (a rate of 27 per cent was found by Perry, Jacobsberg and Fishman, 1990). Marzuk et al. (1988), showed that suicide rates for people with AIDS were over 36 times higher than a demographically matched population and over 66 times higher than the general population. The control groups selected here have been criticised, and the sample (New York residents in 1985) may limit generalisation. However, more stringent epidemiological research has not yet been carried out on suicide rates in HIV infection (O'Donnell, Catalan, Farmer, 1992).

Summary

A wide range of psychological problems have been found in reaction to HIV infection at all stages of testing and illness. These have included typically: anxiety, depression, and adjustment problems.

1.3 Psychological impact of HIV on affected individuals:

No illness concerns only the patient and there are emotional, social and economic repercussions for those close to the infected person (King, 1993). There has been limited investigation of the impact of HIV on carers and other

affected people. This is despite the arguments of Raveis and Siegel (1991) that care for a partner with HIV is more stressful than for other illnesses due to:

a) **disease characteristics** - There is much uncertainty, unpredictability and uncontrollability of symptoms and there can be disfiguring and debilitating effects;

b) **carer characteristics** - The carer is typically a young male partner whilst with other illnesses the burden of care is usually met by families, and the typical carer is an older female relative. There is thus none of the societal support and role-expectation for being a carer. In HIV infection the family may be negative and rejecting, leaving friends and partners, as the principal support (e.g. McCann and Wadsworth, 1992, showed that only eight per cent of their sample of men with AIDS identified a parent or sibling as the primary carer). However, an alternative explanation is that the different pattern may be due simply to life-span development issues. Nevertheless, in some cases a rivalry can develop between mothers and partners of gay men with AIDS (Bor, Miller and Goldman, 1993).

c) **societal problems** - There may be difficulties with the lack of acceptance of gay relationships in general society e.g. a need to conceal the relationship from employers. Also AIDS is a socially stigmatised disease and infected people can be met with hostility, prejudice and rejection.

d) **carers' own infection** - The carers may also be infected with HIV, and thus their partners' disease progression can be a prediction of things to come for themselves.

Some of the few studies that have investigated people affected by HIV are outlined below.

Qualitative and descriptive studies

McCann and Wadsworth (1992) surveyed a UK sample of 125 'informal carers' of gay men with HIV related illness. These included close friends, partners, parents and siblings. Fifty-six per cent of the carers felt that they 'bore the brunt' of care. Twenty-eight per cent felt themselves to be inadequately supported either emotionally or practically. Five per cent were in poor health themselves, with ten per cent HIV-positive. No formal measures of distress were used in this study.

Brown and Powell-Cope (1993) conducted in-depth interviews with 53 'family caregivers' of people with AIDS (parents, siblings, partners and friends). Their qualitative analysis of the data showed two major themes: facing loss (the death of their loved one, the loss of their previous relationship, the loss of freedom due to the restrictions of caring) and transformed time (changed perspectives on what is important, putting the future 'on hold'). Carers reported using three strategies to cope: taking one day at a time, living fully in the moment and actualising future plans.

Folkman, Chesney and Christopher-Richards (1994) also provided descriptive data from interviews of 50 partners of gay men with AIDS (no

qualitative research analysis was described). Partners reported difficulties with: adjusting to illness progression; the shifting of responsibility within the relationship; unexpected improvements in health; dealing with a largely uncontrollable disease; role conflicts (e.g. between working and caring); fatigue; and for the caregivers who were themselves HIV positive, fears for their own future. (This study is the initial report from a large scale longitudinal investigation).

Quantitative studies

One study that has used formal measures and a homogeneous sample was Irving, Bor and Catalan (1995). They examined the level of psychological distress in a UK sample of 38 lovers/partners of men with AIDS. 48 per cent were HIV positive and 52 per cent HIV-negative. They found that 21 per cent were 'probable psychiatric cases' whilst 45 per cent were 'definite psychiatric cases' (using the General Health Questionnaire). Partners of men who were medically unstable reported more distress,

Folkman, Chesney and Christopher-Richards (1994) investigated 253 caregiving partners of gay men with AIDS (86 HIV positive and 167 HIV negative). They also used 61 HIV positive with HIV negative partners as non-caregiving controls (but surprisingly no group with both partners HIV negative). None of their sample met criteria for clinical depression (Hamilton rating scale), although the caregivers reported higher levels of dysphoric mood (one SD above national samples) on the Centre for Epidemiological

Studies depression scale. This sample was studied further (Folkman, Chesney, Cooke, Boccellari and Colette, 1994) with regard to the determinants of care-giving burden. This was found to be influenced by the same variables as traditional carers of the frail elderly: the needs of the care-recipient, the quality of their relationship and other stressful life events. This study is described in more detail in later sections as it has specific relevance to the current investigation.

Pakenham, Dadds and Terry (1995) surveyed 34 carers (family, friends and partners) of men with HIV infection (all stages). Only six carers had levels of clinically significant psychological distress (as measured by the Brief Symptom inventory). The study also investigated determinants of this distress and this is similarly discussed in more detail later.

Criticisms of research

Of the few studies that have been performed, many have used heterogeneous samples of parents, partners and friends (e.g. McCann and Wadsworth, 1992, Brown and Powell-Cope, 1993, Pakenham, Dadds and Terry, 1995) although it is likely that there would be significant differences between groups. Control groups have been lacking in all but one study and there has been little use of validated measures. The majority have focused on carers of people with AIDS rather than at all stages of infection. Only two studies have used a UK sample (McCann and Wadsworth, 1992, and Irving,

Bor and Catalan, 1995). There is one longitudinal study in progress, of which only the initial phase has been completed.

Summary:

There have been a few studies investigating the psychological impact of HIV on those close to the infected person. There are a number of methodological weaknesses in these studies. The qualitative studies have described some of the challenges that carers are facing. Levels of distress in the quantitative studies have varied perhaps reflecting either the different samples or the different measures used.

1.4 Stress and Coping:

HIV infection, like other serious illnesses, is highly stressful for both individuals and their partners. There is a large psychological literature on stress and a thorough review is beyond the scope of this introduction.

Complicating the area is that the definition of stress has been used to describe both challenging or threatening events in the environment and the internal responses to these events. Early models of stress conceptualised a simple stimulus-response relationship between demands of the environment and the internal stress response (e.g. Selye, 1976). However, these models were biologically based and did not account for observed variation in individuals responses. Increasingly a consensus has been reached (see Taylor, 1991, Cox, 1995) that stress is best defined as an interaction between person and environment:

"stress may be said to arise when there is an imbalance between the perceived demand and the person's perception of his capability to meet that demand." (Cox, 1978, p.18).

One of the better articulated transactional models of stress is by Folkman and Lazarus (1984). This emphasises the role of cognitive appraisal and coping efforts. Any new event or change in the environment is subject to 'primary appraisal' to determine its significance for the person's well-being. If it is appraised as stressful (involving harm, loss, threat or challenge) then 'secondary appraisal' of the person's ability to cope with the situation takes place. Lazarus and Folkman (1984) define coping as:

"...constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."

Coping therefore describes the range of responses to stress and not the outcome of these efforts. Coping is considered to be a complex, dynamic, multi-dimensional process which may change over the course of a stressful event. A number of different strategies may be used such as gathering information, trying to solve the problem, enlisting the help of friends etc. There have been attempts to group these into higher order theoretical constructs and early theory about coping made a big distinction between problem-focused or emotion-focused coping (see Lazarus, 1993). The function of problem-focused coping is to actively change the environment or

to change something about the self (e.g. level of aspiration) to stop the environment being stressful. In emotion-focused coping the emphasis is on changing the way you feel, reducing the anxiety directly without changing the problem itself. Most stressors elicit both types of coping but problem-focused coping tends to predominate when the problem is changeable in some way and emotion-focused when the problem must be endured. Health related stressors were shown to prompt more emotion-focused coping (Folkman and Lazarus, 1980)

This distinction forms the basis of the empirically derived 'Ways of Coping' scale (Folkman and Lazarus, 1980) which has been widely used in research (e.g. Frank et al. 1987). Carver, Scheier and Weintraub (1989), however, showed that both ways of coping include items that are very diverse (e.g. emotion-focused coping includes denial, positive reinterpretation, and seeking out social support) and factor analysis shows the presence of more than these two factors. They therefore developed their own theoretically derived scale - the COPE. This was devised from factor analysis of the coping responses of over 900 undergraduates. The COPE has fifteen sub-scales (described in detail in the method section). The COPE has been used for investigating a variety of populations including spinal cord injury (Kennedy, Lowe, Grey and Short, 1995) and chronic fatigue (Ray, Weir, Stewart, Miller, Hyde, 1993).

Coping with chronic illness

Chronic illness can be associated with a great deal of distress and the role of coping has been investigated. For example, Felton, Revenson and Hinrichson (1984) showed that wish-fulfilling fantasy (an emotion-focused strategy) was associated with poorer adjustment (acceptance of illness, positive and negative affect and esteem) amongst 170 people with rheumatoid arthritis, cancer, hypertension or diabetes. Information seeking (a problem-focused approach) was associated with better adjustment. No more than eleven per cent of the variance in adjustment was predicted by coping strategies. However, their measure of coping was based on two scales combined and then factor-analysed to give six factors. Felton and Revenson (1984) extended the above investigation to a longitudinal study so they were able to look at direction of causality between adjustment and coping. For problem-focused coping, coping appeared to predict adjustment, whilst for emotion-focused coping there were reciprocal influences.

Bombardier, D'Amico and Jordan (1990) demonstrated that emotion focused coping (specifically wishful thinking, self-blame and avoidance) was associated with depression and poorer illness adjustment in 101 people with a wide range of chronic medical conditions (both physical and psychiatric).

Kennedy et al. (1995) investigated coping in 71 people with spinal cord injury (although response rate was 36 per cent for a subgroup of the study). They showed that coping strategy was more important for predicting adjustment

than degree of disability in spinal cord injury. Acceptance appeared to be most associated with positive adjustment, whilst behavioural disengagement and focusing on / venting emotions were associated with depression.

However, an earlier study by Frank et al. (1987) using cluster analysis found that people with spinal cord injury who reported using few coping strategies actually had lower levels of distress. These two studies can be reconciled as the subjects in the Frank et al. (1987) study who were using more coping strategies were perhaps using more of the styles found to be associated with depression by Kennedy et al. (1995).

Coping strategies have also been investigated with: sickle cell disease (Gil, Abrams, Phillips and Williams, 1992, showed negative thinking and passive adherence were related to poor adjustment); and cancer (e.g. Burgess, Morris and Pettingale, 1988, who found hopeless/helpless coping associated with poor adjustment). Heim (1991) meta-analysed fifteen studies on coping and cancer. He summarised that active/tackling behaviour by patients was associated with better psychosocial adjustment and survival time.

Resignation/fatalism was negatively associated with the above.

To summarise, the literature on chronic illness suggests an association between active-behavioural coping and lower levels of distress.

Coping with HIV infection

Coping strategies used by people with HIV infection have also been investigated. In common with the literature on chronic illness there is an association between active-behavioural coping and positive mood. This link was shown: in 50 men with AIDS (Namir, Wolcott, Fawzy and Alumbaugh, 1987); in 42 men with HIV infection but not AIDS (Hedge, Slaughter, Flynn and Green, 1993); and in 96 men at all stages of infection (Pakenham et al., 1994). Other coping styles were also shown to be associated with positive mood e.g. seeking emotional support (Hedge et al. 1993), optimism, controlling feelings and seeking social support (Pakenham et al., 1994).

Other studies have shown a link between emotion focused coping and higher levels of depression (e.g. DeGenova, Patton, Jurich and MacDermid, 1994, with 85 HIV-positive men). Studies have also found associations between various coping styles and higher levels of depression e.g.: avoidant coping (Nicholson and Long, 1990, with 89 HIV-positive but not AIDS); denial (Lesserman, Perkins and Evans, 1992, with 52 asymptomatic HIV-positive men); and behavioural disengagement (Hedge et al. 1993).

Pakenham et al. (1994) hypothesised that different methods of coping would be optimal at different stages of the disease (problem focused at an asymptomatic stage and emotion focused later). However, they found that coping style and adjustment did not vary across disease stages.

In HIV infection the most consistent finding has been for an association between active-behavioural coping and lower levels of distress, as has been found in research in other forms of chronic illness. However, researchers have tended to use idiosyncratic methods for measuring coping style (e.g. using a few scales from the COPE and a few from an adapted coping with cancer scale - Lesserman et al., 1992). Also definitions of styles of coping vary across studies, making generalisation difficult. The Nicholson and Long (1992) study had a response rate of only 24 per cent suggesting an unrepresentative sample.

Coping with chronic illness - carers

Chronic illness has an impact on carers but there have been few studies looking at their coping strategies. Wacholder (1993) investigated carers (15 partners and 10 parents) of people with spinal cord injury using the COPE. She showed that 'positive reinterpretation', 'active coping' and 'humour', were all associated with carer well-being, whilst 'suppression of activities' was associated with depression (these are subscales of the COPE). However, the small and heterogeneous sample limits this study and there was a response rate of only 30 per cent.

Coping with HIV infection - carers and other affected groups

There have been very few studies looking at the role of coping in caring for someone with HIV infection. Investigating 34 caregivers (family, friends and partners) of HIV-positive men, Pakenham et al. (1995) found a correlation ($r = -.42$

.42, $p < .05$) between problem-focused coping and level of psychological distress as measured by the Global Symptoms Inventory . Their coping measure was the 'coping strategies device' (Viney and Westbrook, 1982) which is not a well validated measure and has only moderate levels of reliability (see later for further criticism of this measure)

Folkman, Chesney, Cooke, Boccillari and Colette (1994) showed that coping style was not significantly related to level of 'care-giver burden' in 244 partners of gay men with AIDS. Care-giver burden was defined as the extent to which the caregiver is bothered by caregiving related disruptions. They did not compare level of distress with coping strategy (although burden and distress were moderately well correlated. In addition their measure of coping (based on the Ways of coping questionnaire) is open to criticism (see later).

To summarise the limited research on carers of people with HIV, the role of coping has not been conclusively demonstrated as especially significant. However, there are criticisms of the way that coping has been measured.

1.5 Other moderating factors

In addition to coping strategy there are many other moderating factors that may also contribute to level of psychological distress in HIV infection. These include: social support, quality of relationship, other stressful life events, previous bereavement due to HIV, and disease stage of the partner.

Social Support:

Social support has long been known as an important variable moderating the impact of stressful events (e.g. Brown and Harris, 1978). There are problems of definition with social support (the existence of interpersonal relationships, the functional content of these relationships whether emotional or instrumental/practical, or their perceived adequacy) and how it should be measured. There is, however, ample evidence that social support is positively linked with health, psychological well-being and negatively related to mortality (Ganster and Victor, 1988). Social support can provide tangible assistance, information and emotional support. Research shows that social support can effectively reduce distress during times of stress (see Cohen and Wills, 1985).

Two models have been described which suggest how social support moderates stress. The 'main effect' model suggests that social support is beneficial whether or not stress is being experienced (e.g. Taylor, 1991) and the 'stress-buffering' model which views social support as beneficial only when stress occurs (Cohen and Wills, 1985). There is evidence supporting both models (e.g. Gatchel, Baum and Krantz, 1989).

Whilst partners are a major source of social support for the person with HIV, they in turn will need to have support. Research outlined below shows the importance of social support for the person with HIV and the partners or carers of people with HIV and other illnesses.

Social support in HIV

The role of social support has been extensively investigated with regard to adjustment to serious illness. Specifically with regard to HIV, Green (1993) reviews eighteen studies looking at social support for HIV-positive individuals and concludes that despite some conflicting findings, there is good evidence that psychological state (ability to cope and low levels of depression) is correlated with satisfaction with, or perceived availability of social support. One major difference between people with HIV and other groups of chronically ill people is that friends rather than family generally provide the main care (e.g. Johnston, Stall and Smith, 1995). Gay men ($N=502$) in the UK reported high levels of social support and good availability of informal care networks (Hart et al. 1990).

Britton, Zarski and Hobfoll (1993) provided some evidence of the stress buffering effect for 60 HIV-positive and 61 HIV-negative men. For those who were HIV-positive, distress was positively related to low perceived social support. This was not found with the HIV-negative men. Noh, Chandarana, Field and Posthuma (1990) showed that inadequate social support was the highest correlate of depression amongst 148 'worried well' facing the perceived threat of AIDS.

Social support is a complex area to research. For example Hays, Magee and Chauncey (1994) investigated what had been helpful or unhelpful behaviour

by members of the support network, for 25 men with AIDS. This varied depending on which network members performed the behaviour and when the behaviour occurred.

Social support for carers:

In the few studies looking at social support for carers there has been a mixed picture of results, perhaps reflecting the different sample groups. The quality of social support was found to correlate with lower levels of depression in 20 partners of older people with dementia (Morris, Morris and Britton, 1989).

However, Wacholder (1993) showed that satisfaction with support was not associated with distress in 25 carers of people with spinal cord injury.

Similarly, Folkman, Chesney, Cooke, Boccellari and Colette (1994) found that social support was not associated with levels of burden in 244 care-giving partners of men with AIDS. However, all of their sample reported high levels of social support. They did not investigate the relation between distress and social support.

Quality of Relationship:

Quality of relationship is known to be an important variable influencing the degree of burden in care-giving. In older adults, Morris, Morris and Britton (1988) showed that caregivers of people with dementia ($N=20$), with lower levels of marital intimacy, (before onset of dementia and at the time of study) had higher levels of strain and depression. This was also found by Gilleard et al. (1984) looking at daughter care-givers of older adults. Generalisation

from these findings may be uncertain as it is known that gay relationships do show certain differences with those of heterosexuals (e.g. Kitzinger and Coyle, 1995, suggest lower levels of cohabitation and monogamy). However, Folkman, Chesney, Cooke, Boccellari and Colette (1994) showed that care-giver burden in partners of gay men with AIDS, was similarly influenced by the quality of their relationship.

Other Stressful life events:

The role of stressful life events in both psychological distress and illness has a long history in psychological research (e.g. Holmes and Rahe, 1967, Brown and Harris, 1978). Research into stressful life events has been widespread (e.g. see Taylor, 1991) but there are a number of criticisms of the measurement of life events (e.g. Grant, Patterson, Olshen and Jager, 1987, suggested a false correlation has been created by defining certain symptoms of stress such as illness, negative life events).

According to the cognitive costs hypothesis (Glass and Singer, 1972) any stressful event requires the expenditure of cognitive resources in order to cope. With a greater number of stressful life events in an individual's life then fatigue and emotional exhaustion can result. Despite theories such as these the impact of additional life events has not been widely considered in the care-giving literature, even though resources that are already stretched by the illness of a partner may be overwhelmed by additional stressors.

Folkman, Chesney, Cooke, Boccellari and Colette (1994) showed that care-

giving burden in partners of gay men with AIDS, was indeed influenced by other stressful life events in the previous year.

Previous bereavements and 'Multiple Loss Syndrome'

Bereavement is known to be associated with distress and a range of other reactions such as anxiety, anger and guilt (e.g. Worden, 1982). One feature of the HIV epidemic is that gay men have often sustained multiple bereavement and decimation of their social network. Significant levels of psychological distress accompany this level of bereavement (e.g. Martin, 1988, Martin and Dean, 1993). There has been some commentary on a 'multiple loss syndrome' where people are in a state of exhaustion and emotional withdrawal (e.g. Hedge, 1991). Previous experience with HIV related loss may therefore be an important moderating variable of distress in people affected by the current HIV infection of a loved one.

Disease stage of the patient

Intuitively, severity of illness, would be thought to be related to increased burden and distress. However, Woods and Britton (1985) reviewed a number of studies looking at care-giver burden and overall severity of illness in the elderly population. There was no link between the two, although some studies showed specific problem behaviours (such as demands for attention) were related to burden. Within the area of HIV, Pakenham et al. (1994) showed that symptomatic HIV positive people were more distressed than

asymptomatic. Despite this Pakenham et al. (1995) showed that there was no association between disease stage and carers' burden.

1.6 Summary and critique of the literature on partners of people with HIV infection

The UK research to date on partners of people with HIV infection is extremely limited. McCann and Wadsworth (1992) published a purely descriptive study of the needs of 'informal carers' (half of whom were partners). Irving et al. (1995) showed that levels of distress were high in the lovers/partners of men with AIDS. However, they did not investigate this distress further by exploring any of the moderating factors described above.

Only two studies have attempted to do this. Pakenham, et al. (1995) investigated an Australian sample of 34 carers of men with HIV infection. Their heterogeneous sample included family, friends and partners (with men and women equally represented) and there are likely to be important differences between these groups (uninvestigated due to the small overall sample size). They looked at the contribution of various factors such as coping strategy and illness severity to psychological distress, carer burden and adjustment to the illness. They found that one coping strategy (action coping) was weakly associated with reduced distress. However, their measure of coping strategy (based on Viney and Westbrook, 1982) is not widely recognised and has only moderate reliability. It appears to have some conceptual confusion. There are six ways of coping recognised (action,

control, escape, fatalism, optimism, and interpersonal coping) none of which appears well defined or based on a sound theoretical basis. A further criticism is there was no attempt to investigate other moderating factors such as social support.

Folkman, Chesney, Cooke, Boccillari and Colette (1994) investigated a large US sample ($N=244$) of partners of gay men with AIDS. They compared caregiver burden with a number of moderating factors such as coping strategy and social support. The sample was larger and more homogeneous. They found significant correlations between coping strategy and burden (specifically active problem solving, distancing, cognitive escape avoidance and seeking social support). There are limitations with their coping measure (based on eight scales of the ways of coping questionnaire - Folkman and Lazarus, 1980). They asked participants to describe one stressful event related to caregiving in the previous week and outline how they coped. Only one experience formed the basis for examination of 'coping style'. There was no examination of whether this event or their response to it, was in any way typical and indeed it is likely that unusual events would be recorded being of higher saliency.

In addition to the methodological limitations outlined above, the generalisation of these findings to a UK sample is uncertain (e.g. given different systems of health and social provision).

1.7 The current study

The current study investigated psychological well-being in the partners (see definition in method section) of gay men with HIV. The study surveyed partners of patients at all stages of HIV infection, unlike some previous studies which have focused specifically on carers of people with AIDS. In addition a UK sample is investigated in more detail for the first time. The current study focused on HIV-negative male partners in order to investigate a homogeneous sample.

The research outlined above shows that there are a number of moderating factors influencing level of distress in the partners of people with various illnesses. The area is highly complex and it is likely that each factor is reciprocally influenced by the other factors. This study focused on coping strategy as these are to some extent in the person's control (unlike disease stage) and can be influenced by mental health professionals. If coping strategy was shown to play a significant role in psychological distress/well-being then this could have important implications for both additional research and advice given to partners.

There are a great variety of challenges and threats faced by partners of gay men with HIV-infection. Some of these challenges will be amenable to change and thus best met by active coping strategies whilst others require more emotion-focused approaches. In addition to specific strategies that may be linked with distress, there is also the possibility that overall number of

coping strategies used may be important. People employing a broad range of strategies rather than relying on a specific strategy or narrow range of strategies could have higher levels of psychological well-being. Alternatively, using too many strategies may mean that none could be used effectively. The primary aim of the current study was to investigate what specific coping strategies are associated with psychological distress/well-being (see hypothesis one below) and whether using a broad or limited range of strategy is associated with this distress.

Other moderating factors may also influence level of distress. The current study additionally investigated whether using different coping strategies accounts for a significant amount of the variance in psychological well-being, compared with other factors (social support; quality of the relationship; other stressful life events; previous HIV related bereavement and disease stage of the patient). This leads to hypothesis two below.

Statement of Hypotheses

Hypothesis one:

That there will be an association between number and type of coping strategy used and psychological distress/well-being.

(Null hypothesis: That there will be no association between number and type of coping strategy used and psychological distress/well-being.)

Hypothesis two:

That differences in coping strategy used account for a significant amount of the variance in psychological distress/well-being compared to other known moderating factors.

(Null hypothesis: That differences in coping strategy used do not account for a significant amount of the variance in psychological distress/well-being compared to other known moderating factors).

Subsidiary hypotheses

The current study also investigated a number of other hypotheses regarding the role of suspected moderating factors (from the literature outlined above) in the level of psychological distress/well-being of the partner.

Hypothesis three:

That there will be an association between social support and psychological distress/well-being.

(Null hypothesis: That there will be no association between social support and psychological distress/well-being).

Hypothesis four:

That there will be an association between quality of relationship and psychological distress/well-being.

(Null hypothesis: That there will be no association between quality of relationship and psychological distress/well-being.).

Hypothesis five:

That there will be an association between other stressors and psychological distress/well-being.

(Null hypothesis: That there will be no association between other stressors and psychological distress/well-being.).

Hypothesis six:

That there will be an association between previous experience of HIV infection and related bereavement and psychological distress/well-being.

(Null hypothesis: That there will be no association between previous experience of HIV infection and related bereavement and psychological distress/well-being.).

Hypothesis seven:

That there will be an association between the patients' health and the partners' psychological distress/well-being.

(Null hypothesis: That there will be no association between the patients' health and the partners' psychological distress/well-being.).

2.0 METHOD

2.1 Participants

Selection criteria for the study were: to be the (HIV-negative) current male partner of a man with HIV infection. Partners were people self-defining as such, in committed relationships of more than six month's duration (checked by a question in the last section of the questionnaire). Heterosexual partnerships were excluded from the study as there were insufficient numbers attending the services, and they were not the focus of the study. 'Partners' will henceforth be used to refer to the participants of the study, and 'patients' to refer to *their* partners with HIV infection.

2.2 Design

A cross-sectional questionnaire design was used. The dependent variables were measures of mood, psychological distress and well-being (outlined in more detail below). The independent variables were: measures of coping strategy; social support; stress and life events; relationship quality; previous experience of HIV infection and bereavement; and a number of demographic, health, carer burden and service related questions (outlined fully below). All participants were given all measures.

2.3 Measures

The full questionnaire is shown in Appendix 1. The measures that comprised it are described in detail below.

Dependent Measures

The Hospital Anxiety and Depression Scale (HADS).

Anxiety and depression were measured by the HADS. This is a fourteen item scale developed by Zigmond and Snaith (1983) to provide a state measure of anxiety and depression, without contamination by physical symptomatology. There are two subscales, one for anxiety and one for depression, with seven questions for each. Respondents are asked to rate the applicability of statements (scores range from 0-3 for each statement).

Scores of 8-10 on each scale are taken to indicate possible psychiatric disorder, whilst 11 or above indicates probable psychiatric disorder. Internal consistency is high with Cronbach Alpha scores of 0.93 and 0.90 for anxiety and depression respectively (Moorey et al., 1991). Face validity is high and respondents find it easy and acceptable. Concurrent validity is also high (Zigmond and Snaith, 1983).

General Health Questionnaire (GHQ-28).

Psychological distress was also measured with the GHQ-28 (Goldberg and Hillier, 1978). This was designed to detect 'cases' of psychiatric disorder and to give some indication of the type of disorder and its severity. It consists of four subscales: somatic symptoms; anxiety and insomnia; social dysfunction; and severe depression. For each item the respondent is asked whether they have experienced a particular symptom or behaviour using a four point scale ('less than usual', 'same as usual', 'rather more than usual' and 'much more than usual'). There are two forms of scoring: the GHQ method where

responses score 0, 0, 1, and 1; and the Likert method where responses score 0, 1, 2, and 3 respectively. The Likert method is more useful for comparing degree of disorder and is used in the current study, although the number of cases was also computed for comparison with other studies.

Coping outcome is not just the avoidance of negative emotions but also the ability to experience subjective well-being. Measures of well-being were therefore included in addition to the above measures of psychological distress. Well-being is thought of as comprising two components: positive affect; and life satisfaction (a cognitive/judgmental component).

Positive states of mind scale (PSOM)

Positive affect was measured with the PSOM (Horowitz, Adler and Kegeles, 1988). It was developed from clinical experience of the impact of traumatic events. The scale assesses the following types of positive mood: focused attention; productivity; responsible caregiving; restful repose; sensual pleasure; and sharing. Respondents are asked to rate the ability to achieve each state of mind on a four point scale. Internal consistency is reported as high (Cronbach's alpha = 0.77) although so is social desirability (correlation 0.22, $p < 0.003$). It correlates positively with the number of favourable adjectives endorsed and negatively with unfavourable adjectives and measures of negative affect.

Satisfaction with Life Scale (SWLS)

Satisfaction with life was measured using the SWLS (Diener, Emmons, Larsen and Griffin, 1985). This is a five-item self-report scale in which respondents rate their level of agreement with a statement on a seven-point scale. Scores range from 5 (minimal life satisfaction) to 35 (best possible). The SWLS has good reliability (test-retest correlation, 0.82) and internal consistency (coefficient alpha, 0.87). Factor analysis has shown one factor accounting for about 70 per cent of the variance. It correlates positively with other measures of subjective well-being, self esteem and interviewer ratings of life satisfaction. It is not contaminated by social desirability responses (as measured by the Marlowe-Crowne Scale). Diener et al. (1985) reported means of 23.5 (SD=6.43) for a student sample and 25.8 (SD not specified) for an older adults sample.

Independent Measures

The COPE

Coping strategy was measured using the COPE (Carver et al., 1989). This is a multidimensional coping inventory with fifteen scales (shown in Table 1), each comprising four items.

Table 1: sub-scales of the COPE

Sub-scale	Description
1. Active coping	taking action or exerting efforts to remove the stressor
2. Planning	thinking about how to confront the stressor, planning one's active coping efforts;
3. Seeking instrumental social support	seeking assistance, information, or advice about what to do
4. Seeking emotional social support	getting sympathy or emotional support from someone
5. Suppression of competing activities	suppressing one's attention to other activities in which one might engage, in order to concentrate more completely on dealing with the stressor
6. Religion	increased engagement in religious activities
7. Positive reinterpretation and growth	making the best of the situation by growing from it, or viewing it in a more favourable light
8. Restraint coping	coping passively by holding back one's coping attempts until they can be of use
9. Acceptance	accepting the fact that the stressful event has occurred and is real
10. Focus on and venting of emotions	an increased awareness of one's emotional distress, and a concomitant tendency to ventilate or discharge those feelings
11. Denial	an attempt to reject the reality of the stressful event
12. Mental disengagement	psychological disengagement from the goal with which the stressor is interfering, through daydreaming, sleep or self-distraction
13 Behavioural disengagement	giving up, or withdrawing effort from, the attempt to attain the goal with which the stressor is interfering
14. Alcohol/drug use	turning to the use of alcohol or other drugs as a way of disengaging from the stressor
15. Humour	making jokes about the stressor

The scales were developed from a factor analysis of the sixty items, except that both forms of social support loaded onto a single factor, as did 'active coping' and 'planning'. The 'alcohol/drug' use and 'humour' scales were developed after the other scales and are considered exploratory by the authors. Scales 1, 2, 5, 7, and 8, (see Table 1) are considered by the authors to be adaptive in situations where active coping efforts yield good outcomes. Scales 3, 4, and 6 are considered to be probably adaptive in these situations. The authors comment that it is less clear what strategies

would be most adaptive when the situation is uncontrollable (such as with aspects of the patient's HIV infection).

The COPE can be used as either a dispositional version (how one usually copes with stressful events) or a situational version (how one copes with specific situations or during a specific time period). In the current study the situational version was used (see Appendix 1 for the full instructions). Scores for each scale are computed by adding the scores for each of the four items (ranging from 1, 'I don't do this at all', to 4, 'I do this a lot'). The scores for each scale can range from 4-16.

Internal consistency is reasonably high (Cronbach's alpha > 0.6) for all the scales except 'mental disengagement'. Construct validity was tested by comparing with various personality traits thought to be associated with particular forms of coping. As predicted, selected scales (active coping, planning, positive reinterpretation and growth) were found to positively correlate with measures of optimism and self esteem, and negatively correlate with trait anxiety. Denial and behavioural disengagement displayed the opposite pattern.

Short Form Social Support Questionnaire (SSQ6)

Social support was measured by the SSQ6 (Sarason, Sarason, Shearin, and Pierce, 1987). This gives a measure of both number of supports available and satisfaction with these supports. There is high internal consistency

(Cronbach's alphas > 0.90), high test-retest reliability and a single factor accounting for the majority of the variance in each subscale. Sarason et al. (1987) have compared their scale with other social support measures and consider it to be more sensitive. The main drawback is that it does not distinguish between different types of social support (e.g. emotional or practical).

A measure of carers social support

In order to investigate the different types of social support, a measure based on the method of Lennon, Martin and Dean (1990) was used. They asked four simple 'yes'/'no' questions: "Were there other people who could be relied upon to help in the caretaking responsibilities?" (availability of instrumental social support); "Were more such people required?" (adequacy of instrumental social support); "Were there other people available to talk about the emotional difficulties or pain resulting from your partner's infection or illness?" (availability of emotional social support); and "Were more such people needed?" (adequacy of emotional social support). No psychometric data are available on these questions and the use of them in the current study is exploratory, in order to supplement the more recognised measure of social support.

Life events inventory

Life events were measured using a scale developed by Nott and Vedhara (1995). They suggested that targeting life event inventories more specifically

helps to increase the sensitivity of these measures. There have been two life events inventories designed specifically for gay men. The Gay affect and life events scale (Rosser and Ross, 1989) and the scale by Nott and Vedhara (1995). The latter is considerably shorter and easier to complete and thus was selected for the (already long) questionnaire. It includes both a rating of overall stress, a list of specific stressful life events, and a rating for the impact of each of these specific life events. In addition space is provided to allow additional events to be added. It thus provides a measure of the overall stress experienced over the previous six months, the number of specific recent life events and the mean impact of these events. Internal consistency is high with correlation between the overall stress reported and the mean impact of life events ($r=.59$). Construct validity was tested to some degree by showing that the three sub-scales of the inventory correlated positively with negative affect.

The Golombok Rust Inventory of Marital State (GRIMS)

Relationship quality was measured using the GRIMS (Rust, Bennum, Crowe and Golombok, 1988). This has 28-items and respondents are asked to fill in whether they agree or disagree with a series of statements. It was originally designed for heterosexual couples who are married or live together.

However, the manual suggests that it may be suitable for gay relationships, although no standardisation data exist for such. Some minor adaptations were made to make the GRIMS appropriate for a gay population (changing "marriage" to "relationship" and "committed relationship" - items 11 and 23

respectively). Lower scores indicate better quality relationships, although for very low scores the manual suggests that caution should be exercised as the respondent may not be wholly truthful.

Split half reliability is high (> 0.81 for both a clinical and G.P. group) and internal consistency is also high (Cronbach's alpha > 0.85 for the same groups). The authors also investigated construct validity by comparing scores with the clinical interviews of over a hundred individuals in relationships.

Previous experience of HIV infection and bereavement

Previous experience of HIV infection and bereavement was assessed by a series of questions. These asked the respondent to give the number of partner's, friends and family members that he had known with HIV infection and who had died through HIV related illness (see Appendix 1).

Demographic, health and contact with services

A number of further questions were added to the above measures to investigate demographic, health and other variables. Many of these questions were based on the clinical experience of a psychologist with a large amount of experience in the area. These included: the partner's age, education, ethnicity, health and sero-status; the length of relationship and whether they were cohabitating; the patient's age, education, ethnicity, health, diagnosis, symptomology, CD4 count, medication, length of

diagnoses, length of partner's knowledge of diagnoses, care requirement, problems with providing care; and services used by both the partner and the patient.

2.4 Procedure

Following discussion with the Medical Director and other Consultants the study was presented at a multi-disciplinary team meeting for suggestions. Ethical approval was then sought and given by the local ethics committee (Appendix 2). Arrangements for dealing with distress elicited or uncovered by the study are outlined below.

Recruitment of volunteers was done in the following ways:

Group A - from the main trust hospital

Invitations (with a contact telephone number) to participate in the study were left on the reception desk of the HIV out-patient clinic (see Appendix 3).

Posters were also placed in the clinic, describing recruitment characteristics and asking people to take one of the invitations for their partner. Patients on the in-patient wards with partners were identified by other medical personnel.

The patients were then directly approached by the researcher. The study was described and if consenting, they were given an invitation leaflet for their partner. If the partner was present then they were directly approached (with the patient's consent), the study was described and they were invited to participate.

Group B - from the other trust hospital

In order to increase the sample size, posters were also put up in the HIV outpatient clinic of the other trust hospital, with a contact number.

Group C - press adverts and other services

Finally, press adverts (Appendix 3) were placed in a voluntary sector HIV newsletter, and another free newspaper aimed at the gay and lesbian community. Posters were also put in local voluntary services for people with HIV (where they existed, ethical approval was sought from the relevant committees for these services - Appendix 2).

Partners who were directly approached by the researcher were given information leaflets (Appendix 4) and any questions they had were discussed. They were then asked to provide written consent (Appendix 4).

Questionnaires were either completed in the hospital with the researcher present, or they were taken away to be completed and returned by post. The complete questionnaire battery took about 45 minutes to complete. Partners who phoned the contact number were invited to attend the hospital at a convenient time. The procedure then continued as above. If partners were not able to come to the hospital, questions regarding the study were answered over the telephone. The information leaflet, consent form and questionnaire were then posted to them. Envelopes were marked in order to identify the source of the partner.

Arrangements for dealing with any distress elicited by completing the questionnaire were made as follows. If the questionnaire was completed with the researcher present then this could be discussed immediately and a future session arranged. For the postal completers, contact numbers were displayed at several points in the questionnaire and information leaflet. A session would then be offered or appropriate steps to take would be discussed. However, no participant reported distress and several commented on the beneficial effects of taking part. This included feeling that their experience was considered of value.

If participants wished to receive feedback on the results of the study they were invited to include an address for this to be sent. Arrangements were also made to present the research to the staff groups that had assisted.

3.0 RESULTS

The results are presented in the following order: sample size and response rate; investigation of differences between sample groups; demographic data for the sample; descriptive data for the dependent variables; and investigation of the hypotheses. All statistical analyses were performed using SPSS for Windows.

3.1 Sample size and response rate

Thirty-nine participants completed questionnaires of which four were excluded (two participants were themselves HIV positive, one questionnaire arrived after data had been analysed and one participant had completed the questionnaire with regard to a deceased partner). One participant did not complete the COPE scale and there were missing data for some other sections (e.g. the stress overall score which only 21 people completed).

As this was an opt-in volunteer study it is not possible to know how many patients took invitations for their partners who did not wish to take part. Of 27 partners/patients directly approached by the researcher, two partners refused, one patient refused on behalf of his partner, and three partners failed to show up for booked appointments (a response rate of 78 per cent).

35 people were included in the final sample. 26 were recruited from the main trust hospital (group A), 4 from the other trust hospital (group B) and 5 from the press advertisements (group C).

3.2 Differences between sample groups

Different sources of recruitment may result in differences in variables of interest. Analyses were therefore performed to investigate whether the three groups differed. As groups B and C had so few members it was not possible to do Kruskal-Wallis 1-way ANOVA's. It was therefore decided to combine groups B and C (where doing so would not artificially mask differences between these and A) and perform Mann Whitney U tests where possible. A total of 46 variables were examined in this way.

Only two variables showed significant differences between the two groups: 'educational attainment of the patient' ($U=64$, $p=.048$, 2-tailed, corrected for ties) and 'number of days off sick in previous year (partner)' ($U=47$, $p=.006$, 2-tailed corrected for ties).

Where the variable was a 'yes'/'no' response, Chi-square tests were performed to check for differences between groups (five variables). Chi-square tests were non-significant for: 'cohabitation', 'availability of emotional social support', and 'availability of instrumental social support'. However, the 'adequacy of emotional social support' variable showed significant differences between groups (Chi-square= 5.846, d.f. 1, $p = .016$). For the variable 'number of people sharing the house' Fisher's exact test (for small frequencies) was used, due to low expected frequencies. There were no significant differences between groups on this variable ($p= .095$).

For the rest of the variables ($N=26$) scatter plots were created to examine differences between the three groups (see examples in Appendix 5). On examination there were no obvious differences.

Implications of statistical analyses for differences between groups

For 94 per cent of the variables tested there were no significant differences found between the groups. In addition, for the variables that it was not possible to statistically examine, there were no obvious differences between the three groups on examination of the scatter plots. It was therefore decided to consider the sample as homogenous for the purposes of further analysis.

However, although the majority of variables showed no differences between the groups (and five per cent of the time, significant differences would be found by chance) caution was considered to be necessary in interpreting any results from the three variables that showed significant differences ('educational attainment of the patient', 'number of days off sick in previous year (partner)' and 'adequacy of emotional social support'). The actual values for the different groups on these variables are shown in Table 2 below. The 'main hospital' group had taken more days off sick in the previous year (although from examination of the scatter plot they did not rate their overall health as significantly worse). They also had lower levels of 'adequacy of emotional support'. The 'other hospital' group had patients with lower educational attainment.

Table 2: Group Values for the variables showing significant differences between sample groups

	mean number of days off sick in the previous year (partner)	median education level of the patient	adequacy of emotional social support (% of yes responses)
<u>Main trust hospital</u> (group A)	5.92 (SD 9.59)	F.E college	42%
<u>Other trust hospital</u> (group B)	0 (SD 0)	left school at 'O'level	75%
<u>press adverts</u> (group C)	1.2 (SD 2.68)	F.E. college	100%

3.3 Description of the sample

Based on these analyses the three groups were considered to be similar enough to be combined into one large sample ($N=35$). Descriptive statistics are shown for the demographic and other data (Table 3). The typical partner in this study was white, in his late 30's and University educated. Their partners (the patients) were also white and in their late 30s. The average length of relationship was just over six and a half years, and most couples were living together.

Partners rated their own health as 'good' (on average). They were HIV negative and used fewer than one statutory or voluntary service for people affected by HIV. On average, they provided two types of help for the patient (from six options: help with mobility, eating, bathing, toileting, emotional and financial support).

Table 3: Descriptive statistics for demographic and other data for the complete sample

<u>variable</u>	<u>mean (median or mode)</u>	<u>SD</u>	<u>range</u>	<u>N</u>
age of partner (years)	37	7.53	22-59	34
age of patient (years)	36.6	6.61	25-51	35
education of partner (median)	(University)		'O level' - 'postgrad'	35
ethnicity of partner (mode)	(white)			34
ethnicity of patient (mode)	(white)			34
length of relationship (years)	6.59	5.26	0.5-19	35
cohabiting (% saying 'yes')	82.4%			34
sharing house with others (% saying yes)	7.1%			28
Partner				
overall health (median)	('good')		'excellent'-'fair'	35
HIV status (mode)	(HIV-negative)			35
no. current health problems	0.69	0.99	0-4	35
no. HIV services used	0.69	0.93	0-3	35
no. HIV voluntary services used	0.14	0.43	0-2	35
no. types of help partner provides to patient (out of six options)	2.08	1.56	0-5	35
Patient				
no. HIV services used by patient	1.77	0.97	0-3	35
no. HIV voluntary services used by patient	0.57	0.95	0-3	35
no. HIV related drugs taken by patient	1.31	1.41	0-5	35

Dependent Variables

Table 4 shows descriptive statistics for the levels of psychological distress and well-being of the participants. On the HADS anxiety scale fifteen people (42.9 per cent) scored in the 'probable psychiatric disorder' range and six people (17.1 per cent) in the 'possible psychiatric disorder' range. On the HADS depression scale one participant (2.9 per cent) scored in the 'probable psychiatric disorder range' and seven participants (20 per cent) scored in the 'possible psychiatric disorder' range. With the GHQ(28) nineteen participants (54.3 per cent) scored as psychiatric 'cases' (using a threshold of five or above, GHQ method of scoring).

With the Positive States of Mind Scale (PSOM) the mean score was 12.69 (SD 4.10). There was a mean of 20.68 (SD 8.74) on the Satisfaction with Life Scale (SWLS). There are no normalisation data for these two measures.

All dependent variables were tested with the Kolmogorov-Smirnov 1-sample goodness of fit tests for a normal distribution. A normal distribution was not rejected for any of the variables.

Table 4: Descriptive statistics for dependent variables

<u>variable</u>	<u>mean</u>	<u>SD</u>	<u>range</u>	<u>N</u>
HADS anxiety	9.37	4.78	1-20	35
HADS depression	4.23	3.46	0-12	35
GHQ total	26.51	13.57	6-73	35
Positive States of Mind (PSOM)	12.69	4.10	6-18	35
Satisfaction with Life Scale (SWLS)	20.68	8.74	5-35	34

3.4 Investigation of association between the demographic data and levels of psychological well-being

Association between the dependent variables and the demographic data was explored using correlational analysis. Pearson's correlations were used for age of partner and patient and the length of relationship (as Kolmogorov-Smirnov tests did not reject normal distribution). Two-tailed significance levels were used as the direction of association was not predictable. There were significant ($p < .05$) associations only with length of relationship. The longer the relationship the higher the levels of HADS anxiety and depression.

Table 5: Correlation between demographic data and dependent variables

<u>variable</u>	<u>HADS anxiety</u>	<u>Correlation HADS depression</u>	<u>Coefficient GHQ total</u>	<u>PSOM</u>	<u>SWLS</u>
age of partner (r =)	.251	.287	.152	-.012	.045
age of patient (r =)	.281	.231	.157	-.184	-.027
education of partner (rho=)	.141	.006	-.104	.045	.026
education of patient (rho=)	.072	-.005	-.129	-.012	.161
ethnicity of partner	all partners were white				
ethnicity of patient (rho=)	-.212	-.291	-.233	.431	.007
length of relationship (r=)	.370*	.436*	.223	-.229	-.227

* - p<.05; ** - p<.001, 2 tailed

r= Pearson's correlation coefficient, rho=Spearman's correlation coefficient

3.5 Investigation of the hypotheses

In the investigation of hypotheses all variables were tested using Kolmogorov-Smirnov goodness of fit tests. Parametric statistics were used where a normal distribution was not rejected. The hypotheses were examined using 2-tailed significance levels.

Hypothesis one: That there will be an association between number and type of coping strategy used and psychological distress/well-being,

There are two parts two this hypothesis: the number of coping strategies and the type of coping strategy.

Number of coping strategies

'Number of coping strategy used' was considered to mean both the actual number of coping strategies used and a measure of the overall intensity of their use. One way of computing the total was by counting the number of strategies that had been endorsed as being used 'a medium amount' or 'a lot' (a score of three or four on any of the four items of the subscale). A subscale for which an individual scored more than eight (scores ranged from four to

sixteen) was counted as that coping strategy being used. The mean for the COPE total (counting method) was 6.61 (SD 3.16, range 0-15). This gives a measure of the overall number of coping strategies used (but no indication of the intensity of their use).

A second way of computing the COPE total was by simple addition of the scores on each COPE subscale. This gives a measure of the overall intensity of coping across all the subscales. Mean for the COPE total (adding method) was 123.12 (SD 20.97, range 82-176).

The first part of the hypothesis was tested by calculating the correlations between the COPE totals and the dependent measures. Both ways of calculating the COPE total showed significant ($p < .05$) positive correlations with the HADS anxiety scale (see Table 7). There were no other significant correlations with the other dependent measures. There is thus partial support for hypothesis one that there will be an association between number of coping strategy and psychological distress.

Type of coping strategy

The second part of the hypothesis concerned 'type of coping strategy'. This was investigated using the fifteen subscales of the COPE. The descriptive data for the COPE subscales are presented in Table 6. The three most intensively used strategies were: acceptance, positive reinterpretation, and

planning. The three least intensively used strategies were: religion, denial, and behavioural disengagement.

Table 6 - Descriptive statistics for the COPE, (n=34)

subscale	mean	SD	range (4-16 possible)
acceptance	13.15	2.36	8-16
active coping	9.32	2.68	4-15
alcohol/drugs	6.53	3.03	4-16
behavioural disengagement	5.94	1.87	4-11
denial	5.44	1.64	4-10
humour	6.26	2.54	4-12
focus/vent emotions	8.56	3.34	4-16
mental disengagement	7.41	2.32	4-14
planning	9.82	2.98	5-16
positive reinterpretation	10.50	2.36	7-16
religion	5.29	2.70	4-15
restraint coping	8.59	2.55	5-14
emotional social support	9.47	3.56	4-16
instrumental social support	7.76	3.58	4-16
suppression of competing activities	9.06	2.91	4-14

Hypothesis one was tested by calculating the correlations for the individual subscales with the dependent measures. The results of these correlations are shown in Table 7.

Table 7: Correlations between the COPE and the dependent measures

variable	HADS anxiety	Correlation HADS depression	Coefficient GHQ total	PSOM	SWLS
COPE total, adding method (r=)	.457*	.134	.250	-.305	-.018
COPE total, counting method (r=)	.339*	.115	.246	-.053	-.183
acceptance (r=)	-.303	-.512*	-.439*	.349*	.296
active coping (r=)	.251	-.033	-.100	-.034	.259
alcohol/drugs (rho=)	-.013	-.044	.125	-.181	-.323
behavioural disengagement (r=)	.642**	.577**	.509*	-.359*	-.079
denial (rho=)	.222	.106	.232	-.192	-.217
humour (r=)	.092	-.013	.238	-.236	-.332
focus/vent emotions (r=)	.377*	.108	.170	-.250	-.058
mental disengagement (r=)	.510*	.302	.476*	-.360*	-.284
planning (r=)	.319	.113	.224	-.116	.068
positive reinterpretation (r=)	-.031	-.210	-.261	.183	.338
religion (rho=)	.159	.016	.036	.053	.112
restraint (r=)	.190	-.030	-.039	-.210	.046
emotional social support (r=)	.077	-.111	-.040	-.087	.096
instrumental social support (r=)	.229	.066	.087	-.185	.011
suppression (r=)	.614**	.400*	.412*	-.560*	-.122

* - p<.05; ** - p<.001, 2 tailed

r= Pearson's correlation coefficient, rho=Spearman's correlation coefficient

Several of the subscales showed significant correlations with the dependent variables. Higher scores on the HADS anxiety scale were associated with using more behavioural disengagement, mental disengagement, focus/venting emotions and suppression of competing activities. Higher scores on the HADS depression scale were associated with using more behavioural disengagement or suppression of competing activities. Lower scores on the HADS depression scale were associated with more acceptance. Higher scores on the GHQ were associated with more behavioural disengagement, mental disengagement, and suppression of competing activities. Lower scores were associated with more acceptance. Higher scores on the PSOM were associated with more acceptance. Lower scores were associated with more behavioural disengagement, mental disengagement, and suppression of competing activities.

Summary

There was some evidence to support hypothesis one (that number and type of coping strategy used would be associated with psychological distress/well-being). Using more coping strategies was associated with higher levels of anxiety. Significant correlations were also found between psychological distress/well-being and several specific coping strategies (acceptance, behavioural disengagement, mental disengagement, focus/venting emotions and suppression of competing activities).

[Hypothesis two is shown at the end of the results section as selection of variables to test the hypothesis relies on testing of hypotheses three to seven]

Hypothesis three: That there will be an association between social support and psychological distress/well-being.

Participants had a mean number of social supports of 17.85 (SD 13.29, range 1-54) and a mean satisfaction with these supports of 29.00 (SD 6.54, range 10-36). There are no normative data with which to compare this level of support. However the mean response for satisfaction corresponds to a rating of 'fairly satisfied' for each item.

Over 69 per cent of participants said that there was instrumental social support available for assisting caring and 67 per cent of the sample reported an adequate level of instrumental social support. 79 per cent of the sample said that emotional social support was available to assist in caring and 54 per cent reported an adequate level of emotional social support (although note the previously mentioned differences between sample groups for this variable).

Hypothesis three was tested by computing the correlations between the Social Support Questionnaire and the dependent variables (see Table 8).

The number of supports was significantly positively correlated with the Satisfaction with Life Scale. The greater the number of supports the higher

the satisfaction with life. Satisfaction with these supports was significantly negatively correlated with HADS depression, GHQ, and positively with the PSOM and SWLS. The greater the satisfaction with social support the less psychological distress and greater psychological well-being.

In addition Mann Whitney U tests were performed comparing the dependent measure scores of those with and without adequate or available, emotional or instrumental social support (as these gave yes/no responses). Only one result was significant: the 'adequacy of instrumental social support' showed differences on the HADS anxiety scale ($U=61.5$, $p=.023$, 2-tailed corrected for ties). Those who needed more instrumental social support were significantly more anxious than those who had adequate instrumental social support.

Table 8: Pearson's Correlations between the Social Support Questionnaire and the dependent measures

variable	HADS anxiety	Correlation HADS depression	Coefficient GHQ total	PSOM	SWLS
Number of supports	-.005	.062	-.139	.312	.489*
Satisfaction with these supports	-.171	-.359*	-.486*	.484*	.674**

* - $p<0.05$; ** - $p<0.001$, 2-tailed

Summary

There was some evidence to support hypothesis three (that social support would be associated with psychological distress/well-being). Satisfaction with support seemed to be more important than actual number of supporters. There was also a significant association between those without enough instrumental (practical) social support in caring for the patient and increased anxiety levels.

Hypothesis four: That there will be an association between quality of relationship and psychological distress/well-being.

The mean score for the Golombok Rust Inventory of Marital State (GRIMS) was 23.74 (SD 11.38, range 8-48). A lower score indicates a higher quality relationship. The raw scores for ten respondents in the present sample were in the 'undefined' region for scores. The manual suggests that the respondents are either "lying" or "their relationship is at such a tender stage that prediction of its future course would be invalid on the basis of their responses alone." However, the GRIMS was not designed for gay couples or where one partner has a life-threatening illness. It is therefore not possible to conclude that these respondents are accurately placed in the 'undefined' region. All scores were therefore included and the results considered with caution.

Hypothesis four was tested by computing the correlations between the GRIMS and the dependent variables (see Table 9). There was a small but significant negative correlation with the satisfaction with life scale. The better the relationship quality the higher the satisfaction with life.

Table 9: Pearson's Correlations between the GRIMS and the dependent measures

<u>variable</u>	<u>HADS</u> <u>anxiety</u>	<u>Correlation</u> <u>HADS</u> <u>depression</u>	<u>Coefficient</u> <u>GHQ total</u>	<u>PSOM</u>	<u>SWLS</u>
GRIMS	-.022	.072	.064	-.187	-.359*

* - p<.05; ** - p<.001, 2-tailed

Summary

There was some evidence to support hypothesis four (that relationship quality would be associated with psychological distress/well-being).

There was a significant small correlation between better relationship and satisfaction with life.

Hypothesis five: That there will be an association between 'other stressors' and psychological distress/well-being.

Mean overall stress score for the sample was 6.24 (SD 1.89, range 3-10).

This corresponds most closely to a rating of 'moderately stressful'. However only 21 participants completed this section (perhaps as it was rather obscured amongst the instructions for completing the measure). A mean of 7.91 (SD 4.81, range 1-19) stressful events was recorded ($N=35$). It should be noted that some of these items overlapped with the patient's health (e.g. item 30: The health of someone you know is HIV positive is deteriorating).

The mean stress rating for these events was 5.68 (SD 1.69, range 1.33-8.50).

There are no normative data available for this measure.

Hypothesis five was tested by computing the Pearson's correlations between the stress measures and the dependent measures. There were significant and quite large positive correlations between both the overall stress rating and the mean stress of events, and the level of HADS anxiety, HADS depression, and GHQ total (see table 10). The more stress the greater the psychological distress. There were significant negative correlations between

all three stress measures and the PSOM scale. The more stress the lower the PSOM score.

Table 10: Pearson's Correlations between Stressful life events and the dependent measures

variable	HADS anxiety	Correlation HADS depression	Coefficient GHQ total	PSOM	SWLS
overall stress	.817**	.701**	.609*	-.705**	-.337
no. stressful life events	.208	.109	.286	-.477*	-.330
mean stress of these events	.526*	.458*	.397*	-.522*	-.155

* - p<.05; ** - p<.001, 2-tailed

Summary

There was strong support for Hypothesis Five (that other stressors would be associated with psychological distress/well-being). What seemed important was not so much the number of life events, but their severity of impact and an overall rating of the amount of stress for the past six months.

Hypothesis six: *That there will be an association between previous experience of HIV infection and related bereavement and psychological distress/well-being.*

There was a mean of 5.85 (SD 6.64, range 0-30) for the number of HIV positive friends that the sample had known. Six people said that the figure was too numerous to count. There was a mean of 3.70 (SD 4.83, range 0-20) for HIV positive deceased friends. Five people said that there were too many to count. With previous HIV positive partners the mean was 0.47 (SD 1.34, range 0-7). With previous HIV positive deceased partners the mean was

0.13 (SD 0.34, range 0-1). None of the sample had experience of HIV infection in their biological family.

Hypothesis six was tested by computing the correlation coefficients for each previous experience of HIV variable with the dependent variables (see Table 11). The only significant correlation was between previous experience of HIV positive deceased friends, and the Satisfaction with Life scale. Those who had experience of more bereavement from HIV positive friends had a greater satisfaction with life.

Table 11: Correlation coefficients between previous experience of HIV and the dependent measures

variable	HADS anxiety	Correlation HADS depression	Coefficient GHQ total	PSOM	SWLS
HIV+ friends (r=)	.133	.006	-.029	.287	.323
HIV+ deceased friends (rho=)	.112	.207	.147	.172	.410*
HIV+ partners (rho=)	-.037	-.086	.149	-.022	-.014
HIV+ deceased partners (rho=)	-.262	-.129	-.031	.293	.162

* - p<.05; ** - p<.001, 2-tailed
r= Pearson's correlation coefficient, rho=Spearman's correlation coefficient

Summary

There was some evidence to support hypothesis six (an association between previous experience of HIV infection and related bereavements and psychological distress/well-being). There was a small but significant positive correlation between HIV related bereavement of friends and satisfaction with life.

Hypothesis seven: That there will be an association between the patients' health and the partners' psychological distress/well-being.

Several variables were used to measure the level of the patient's health: an overall rating was sought from the partner; the mean number of HIV related symptoms; the diagnosis of HIV disease stage; the length of time since these diagnoses; and the amount of time the partner usually and currently spends caring for the patient.

The overall health of patients had a median value of 5 (corresponding to a rating of 'fair', range 1 - 'very good' to 6 - 'very poor'). The mean number of HIV related symptoms was 1.63 (SD 1.73, range 0-7). The most common diagnosis was of AIDS ($N=19$), then asymptomatic HIV infection ($N=9$), and symptomatic HIV infection ($N=6$). The mean length of knowledge: of HIV infection was 4.64 years (SD 3.51, range 19 days - 12 years); of symptomatic HIV infection - 2.70 years (SD 1.97, range 4 days - 6 years); and of AIDS - 1.72 years (SD 1.45, range 4 days - 4.5 years). The usual amount of time caring (over the past month) had a median value of '1-2 hours a day' and a range of 'none' to '16-24 hours'. The current amount of time (over the previous week) had a median value of '3-4 hours a day' and a range of 'none' to '16-24 hours'.

Hypothesis seven was tested by computing the correlations between overall health, length of time of diagnoses, and number of symptoms with the dependent variables (see Table 12). The overall health rating was

significantly correlated with all dependent variables. The better the overall health the lower the HADS anxiety, depression and GHQ score and the higher the PSOM and SWLS scores. Length of time since AIDS diagnosis was significantly positively correlated with depression. Number of symptoms was also significantly positively correlated with HADS anxiety and depression. Current amount of time caring was significantly positively correlated with HADS anxiety, depression, and GHQ. Usual amount of time caring was significantly positively correlated with HADS depression.

Table 12: Correlation coefficients between health measures and the dependent measures

variable	HADS anxiety	Correlation HADS depression	Coefficient GHQ total	PSOM	SWLS
overall health (r=)	.491*	.567**	.433*	-.432*	-.365*
length of time since HIV+ diagnosis (r=)	.108	.038	-.048	.024	.088
since symptomatic HIV infection (r=)	.132	.142	-.026	.210	.163
since AIDS diagnosis (r=)	.174	.474*	.407	-.336	-.408
No. symptoms (rho=)	.406*	.415*	.295	-.150	.075
Usual amount of time caring (r=)	.364*	.435*	.353*	-.177	-.230
Current amount of time caring (r=)	.313	.399*	.302	-.183	-.157

* - $p < .05$; ** - $p < .001$, 2-tailed

r= Pearson's correlation coefficient, rho=Spearman's correlation coefficient

In addition ANOVA's were used to compare the different diagnostic groups' (asymptomatic, symptomatic and AIDS) scores on the dependent variables. Differences approached significance for: HADS anxiety ($F=3.039$, d.f. 2, $p=.062$); and HADS depression ($F=3.300$, d.f. 2, $p=.05$). Partners of people with AIDS were more anxious and depressed than those of the other groups.

Summary

There was some evidence to support hypothesis seven (an association between the patients' health and the partners' psychological distress/well-being). Significant correlations were found between several of the dependent variables and: overall health of the partner; the length of time since an AIDS diagnosis; the number of HIV related symptoms; and the usual and current amount of time the partner spends caring for the patient. There was also a trend toward more anxiety and distress in the partners' of patients at later disease stages.

Hypothesis two: That differences in coping strategy used accounts for a significant amount of the variance in psychological well-being compared to other known moderating factors.

This hypothesis was tested using forward stepwise multiple regression. Variables that had previously been found to correlate significantly with each dependent variable were suggested for the equation and the regression begun. The only exception to this was the overall stress score. Only 21 people completed this measure and so including it would reduce the numbers in the regression equation. However, where the overall stress score was significantly correlated to a dependent variable, so too was the mean stress of events variable (the two were significantly correlated to each other, Pearson's $r=.490$, $p=.024$). It was therefore considered to be acceptable to remove 'overall stress' as much of the variance in dependent measures due to this variable would be 'picked up' by the mean stress.

The results of multiple regression are reported for each dependent variable below:

HADS anxiety

Twelve independent variables were suggested for the regression. These were: COPE total (both methods); COPE behavioural disengagement; COPE focus/vent emotions; COPE mental disengagement; COPE suppression; mean stress of events; overall health of patient; number of HIV related symptoms; current amount of time caring for patient; adequacy of instrumental social support; and length of relationship.

Stepwise multiple regression selected overall health of the patient, COPE behavioural disengagement and COPE focus/venting emotions for the final equation (see Table 13 for the order of entry and relative importance of each variable). 57 per cent of the variance was accounted for (adjusted R square = .574, $F=14.50$ $p<.001$). The residuals were normally distributed (Kolmogorov-Smirnov test $p=.968$). The regression equation is:

$$\text{HADS anxiety} = -8.016 + 1.394 * \text{COPE behavioural disengagement} + 0.376 * \text{COPE focus/venting emotions} + 1.403 * \text{overall health of patient}$$

HADS depression

Eleven independent variables were suggested for the regression. These were: COPE behavioural disengagement; COPE acceptance; COPE

suppression; satisfaction with social support; mean of stressful events; overall health of patient; current and usual amount of time caring for patient; length of time since AIDS diagnosis; number of HIV related symptoms; and length of relationship.

Stepwise multiple regression selected overall health of the patient, COPE behavioural disengagement and COPE acceptance for the final equation (see Table 13). 65 per cent of the variance was accounted for (adjusted R square = 0.645, $F=10.09$ $p=.001$). The residuals were normally distributed (Kolmogorov-Smirnov test $p=.696$). The regression equation is:

$$\text{HADS depression} = 2.248 + 0.926 \cdot \text{COPE behavioural disengagement} - 0.622 \cdot \text{COPE acceptance} + 1.109 \cdot \text{overall health of patient}$$

GHQ total

Eight independent variables were suggested for the regression. These were: COPE behavioural disengagement; COPE acceptance; COPE suppression; COPE mental disengagement; satisfaction with social support, mean of stressful events; overall health of patient; and current amount of time caring for patient.

Stepwise multiple regression selected COPE behavioural disengagement and COPE acceptance for the final equation (see Table 13). 41 per cent of the variance was accounted for (adjusted R square = 0.407, $F=10.59$ $p<.001$).

The residuals were normally distributed (Kolmogorov-Smirnov test $p=.524$).

The regression equation is:

$$\text{GHQ total} = 37.66 + 3.666 \cdot \text{COPE behavioural disengagement} - 2.504 \cdot \text{COPE acceptance}$$

Positive States of Mind (PSOM)

Nine independent variables were suggested for the regression. These were: COPE behavioural disengagement; COPE acceptance; COPE suppression; COPE mental disengagement; satisfaction with social support, number and mean of stressful events; overall health of patient; and length of time since AIDS diagnosis.

Stepwise multiple regression selected COPE suppression, satisfaction with social support and number of stressful events for the final equation (see Table 13). 57 per cent of the variance was accounted for (adjusted R square = 0.567, $F=7.54$ $p=.004$). The residuals were normally distributed (Kolmogorov-Smirnov test $p=.805$). The regression equation is:

$$\text{PSOM} = 14.746 - 7.137 \cdot \text{COPE suppression} - 0.328 \cdot \text{number of stressful events} + 0.241 \cdot \text{satisfaction with social support}$$

Satisfaction with life scale (SWLS)

Five independent variables were suggested for the regression. These were: ; number and satisfaction with social support, overall health; relationship quality (GRIMS); and previous HIV-positive deceased friends.

Stepwise multiple regression selected satisfaction with social support and previous HIV+ deceased friends (see Table 13). 56 per cent of the variance was accounted for (adjusted R square = 0.560, F=15.01 p<.001). The residuals were normally distributed (Kolmogorov-Smirnov test p=.670). The regression equation is:

$$\text{SWLS} = -8.756 + 0.927 \cdot \text{satisfaction with social support} + 0.691 \cdot \text{previous HIV-positive deceased friends}$$

Table 13: Multiple regression analyses

dependent variable	independent variable (in order of entry)	Beta	t	p
HADS anxiety	COPE behavioural disengagement	.547	4.485	<.001
	overall health of patient	.339	2.768	.010
	COPE focus/vent emotions	.263	2.170	.039
HADS depression	COPE behavioural disengagement	.501	3.189	.008
	COPE acceptance	-.424	-2.683	.020
	overall health of patient	.371	2.297	.040
GHQ total	COPE behavioural disengagement	.506	3.479	.002
	COPE acceptance	-.436	-2.996	.006
PSOM	COPE suppression	-.507	-2.970	.012
	satisfaction with social support	.385	2.230	.046
	no. stressful life events	-.384	-2.229	.046
SWLS	satisfaction with social support	.693	4.896	<.001
	HIV-positive deceased friends	.382	2.700	.014

Summary

There was support for hypothesis two (that coping strategy accounts for an important amount of the variance in dependent measures). For example: 41 per cent of the variance in GHQ score was accounted for by two COPE subscales. 57 per cent of the variance in HADS anxiety was accounted for by two COPE subscales and the overall health of the patient. 65 per cent of the variance in HADS depression score was

accounted for by two COPE subscales and the overall health of the patient.

Although total coping strategies were not influential, individual subscales were selected as important by the stepwise multiple regression equations. These included: behavioural disengagement (HADS anxiety, depression and GHQ); focus/venting emotions (HADS anxiety), suppression (PSOM); and acceptance (HADS depression and GHQ).

Other important variables included: overall health of patient (HADS anxiety and depression); satisfaction with social support (PSOM and SWLS); number of stressful life events (PSOM) and previous experience of HIV-positive deceased friends (SWLS).

4.0 DISCUSSION

The current study investigated the level of psychological well-being and distress in 35 partners of men with HIV infection. In line with a previous study (Irving et al., 1995) clinically significant levels of distress were found.

Determinants of this distress were explored for the first time with a UK sample. Coping strategy and other moderating variables were investigated to determine whether there was an association with the level of distress/well-being reported by the sample. Certain coping strategies were found to be significantly associated with the levels of distress/well-being. Other moderating variables (such as satisfaction with social support and the patients' health) also showed significant associations with distress levels.

In the discussion the findings of the current study are described in more detail and put in a theoretical and research context. Alternative explanations for the results are also explored. The limitations of the study and methodological considerations are reviewed. Finally clinical implications and avenues for further research are outlined.

4.1 Summary and discussion of research findings

Levels of psychological distress

Clinically significant levels of anxiety were found in the current sample. On the HADS anxiety scale fifteen people (42.9 per cent) scored in the 'probable psychiatric disorder' range and six people (17.1 per cent) in the 'possible psychiatric disorder' range. The mean level of HADS anxiety (9.37) can be

compared with Moorey et al. (1991) who found mean scores of 5.44 (SD 4.07) for 573 people who had just been diagnosed with cancer (or on first recurrence of cancer). The current sample therefore had higher scores than a group of people facing the threat of cancer.

Levels of depression were less clinically significant. On the HADS depression scale one participant (2.9 per cent) scored in the 'probable psychiatric disorder range' and seven participants (20 per cent) scored in the 'possible psychiatric disorder' range. The mean level of HADS depression (4.23) can also be compared with Moorey et al. (1991) who found a mean score of 3.02 (SD 2.98).

Clinically significant levels of psychiatric disorder (as measured by the GHQ-28) were also found in the current sample. 54.3 per cent scored as psychiatric 'cases'. This is similar to Irving et al. (1995) who found 66 per cent of their sample of partners of people with AIDS were 'cases'.

Unsurprisingly, both these studies showed higher levels than that found in a community sample of 140 gay men (28.6 per cent were 'cases' - Coyle, 1993).

In comparison with studies on carers, Gilleard et al. (1984) found levels of caseness of 57-73 per cent with three samples of supporters of the elderly mentally infirm (from psychiatric services) and Eagles et al. (1987) found levels of 9.3 per cent caseness (GHQ-60) with the spouses of elderly demented people (from primary care). The current sample therefore showed levels of distress within the range experienced by carers in other studies.

Levels of psychological well-being

Levels of psychological well-being were similar to community and carer samples. With the Positive States of Mind Scale (PSOM) the mean score was 12.69 (SD 4.10). This compares to the mean of 12.0 (SD 3.9) with a male college sample ($N=80$) reported by Horowitz et al. (1988). There was a mean of 20.68 (SD 8.74) on the Satisfaction with Life Scale (SWLS). Two student samples ($N=176$ and 136) yielded means of 23.5 (SD 6.43) and 23.37 (SD 6.53) respectively (Diener et al. 1985). Wacholder (1993) found a mean of 18.9 (SD 7.5), with carers of people with spinal cord injury.

The main hypotheses in this study were related to the importance of coping strategy as a moderating factor for psychological distress and well-being.

The results pertinent to this will therefore be discussed first,

The Importance of Coping Strategy

The three most intensively used strategies were: acceptance, positive reinterpretation and planning. The three least intensively used strategies were: religion, denial, and behavioural disengagement. There are no normative data with which to compare these findings. However, Wacholder (1993) found remarkably similar results with carers of people with spinal cord injuries. Acceptance, active coping and positive reinterpretation were the most intensively used strategies in her study, with alcohol/drug use, denial and behavioural disengagement the least intensively used.

The overall number and intensity of coping strategies used was found to be significantly ($p < .05$) correlated with HADS anxiety. The more coping strategies that were being used the higher the levels of anxiety. One possible explanation is that using a large number of coping efforts actually means that none can be used effectively. The finding is similar to Frank et al. (1987) who found that people with spinal cord injury who reported using few coping strategies actually had lower levels of distress. Another explanation is that anxiety was causing people to make a greater number of coping efforts rather than the coping efforts making people anxious. As both the current and the Frank et al. studies were cross-sectional there is no way of knowing direction of causality. A further possible explanation is that this is a chance finding. This is supported by the fact that there were no significant relationships between number/intensity of coping strategies used and any of the other dependent variables.

Several of the subscales of the COPE showed significant correlation with the dependent variables. Degree of correlation rose to as much as $r = .64$ (for behavioural disengagement and HADS anxiety). In addition, some were selected in the regression models as explaining a considerable amount of the variance in the dependent variables.

'Behavioural disengagement' was significantly ($p < .05$) correlated with four of the five dependent measures and selected for the regression models of all

three measures of distress. Behavioural disengagement is defined as: 'giving up, or withdrawing effort from the attempt to attain the goal with which the stressor is interfering'. It is measured by four questions: "I admit to myself that I can't deal with it and quit trying"; "I just give up trying to reach my goal"; "I give up the attempt to reach what I want"; and "I reduce the amount of effort I'm putting into solving the problem." Many of these statements would seem to be symptomatic of the way a depressed person would respond and thus perhaps the correlation with depression is an artefact. However, the correlation with anxiety cannot be explained away so simply. Hedge et al. (1993) similarly found that behavioural disengagement was associated with higher levels of distress in people with HIV infection. This was also found by Wacholder (1993) with carers of people with spinal cord injury using the COPE.

'Suppression of competing activities' was significantly correlated with HADS anxiety and depression, GHQ, and PSOM. It was selected for the regression model of PSOM. It is defined as: 'suppressing one's attention to other activities in which one might engage, in order to concentrate more completely on dealing with the stressor'. This would seem to be an effective active way of coping and indeed is considered by Carver et al. (1989) to be an adaptive strategy when dealing with a solvable problem. This shows the importance of separating coping efforts from coping outcome and the fact that there are no universally applicable adaptive coping strategies. One possible explanation for the finding is that people using this strategy are focusing all their energies

on their sick partner. The patient becomes the focus of life and everything is centred around their existence. Wacholder (1993) similarly found that suppression of activities was associated with higher levels of depression in carers of people with spinal cord injury.

'Mental disengagement' was significantly correlated with HADS anxiety, GHQ total and PSOM. However it was not selected for any of the regression models (perhaps as Carver et al., 1989, found that mental and behavioural disengagement load onto a single factor).

'Focusing on and venting of emotions' was significantly correlated with HADS anxiety and selected in the regression model for this variable. It is defined as: "an increased awareness of one's emotional distress, and a concomitant tendency to ventilate or discharge those feelings." Pakenham et al. (1994) found that controlling feelings (a construct perhaps opposite to venting emotions) was associated with lower levels of distress in people with HIV infection.

'Acceptance' was significantly negatively correlated with HADS depression, GHQ total and positively correlated with PSOM scores. It was selected for the regression models of HADS depression and GHQ. It is defined as:

'accepting the fact that the stressful event has occurred and is real'. It is perhaps surprising that 'denial' did not show any significant association with the dependent measures.

The other subscales showed no significant correlations with the dependent measures. It is surprising that such universally perceived 'good' coping strategies as active coping or positive reinterpretation were not found to be important. This shows again that there are no universally applicable adaptive coping strategies. The findings of the current study are somewhat different to those of Folkman, Chesney, Cooke, Boccillari and Colette (1994). They showed that for HIV negative caregivers burden was significantly ($p < .05$) correlated with distancing and active problem solving. Note in this study that active problem solving is positively associated with burden. Their study did not directly compare levels of distress with coping strategy but caregiver burden was correlated with depression levels (for HIV negative caregivers, $r = .37$, $p < .001$). Also in their study the coping strategies were used to refer to just one caregiving event in the past week and so there is limited comparability with the current study where overall use of coping strategies is examined. Pakenham et al. (1995) found a significant ($p < .05$) association between 'action coping' and lower levels of psychological distress (their sample included family, friends and partners). Action coping is not defined but an example is given: "I try to find out the cause of my problem". This is different to the current study, where active coping was not found to be significantly correlated with distress. This could be due to a different definition of the coping style and indeed the example they give is perhaps most closely related to 'planning' (defined in the COPE as thinking about how

to confront the stressor...). However in the current study planning was not correlated with distress either.

Unlike the two other studies examining coping in carers of people with HIV infection, the current study found that coping strategy predicted considerable amounts of the variance in distress. Possible reasons for this include: the use of a more sensitive measure (the COPE); the examination of general coping with a sick partner, rather than a specific example of coping as in the Folkman study; and the UK nature of the sample.

The current study investigated measures of well-being in addition to measures of distress. Whilst the Positive States of Mind Scale (PSOM) showed a similar (though opposite) pattern to the distress measures, the Satisfaction with Life Scale was noticeably different. For example, there were no significant correlations between coping strategy and the satisfaction with life scale (SWLS). The SWLS measures the cognitive appraisal aspect of well-being. It is noteworthy that the correlation approaching significance ($r=.34$, $p=.051$) is between the SWLS and the 'positive reinterpretation and growth' subscale. This strategy also involves appraisal in an attempt to make the most of the situation or view it in a more favourable light.

Importance of other moderating factors

From the regression equations other predictive variables included: the overall health of the patient (HADS anxiety and depression); Satisfaction with social

support (PSOM and SWLS); number of stressful life events (PSOM); and number of HIV positive deceased friends (SWLS). The significant moderating factors are looked at in more detail below.

Social support

Satisfaction with social support did seem to be an important variable. It was significantly correlated with all of the dependent measures except HADS anxiety. Number of social supports was associated with satisfaction with life. Folkman, Chesney, Cooke, Boccillari and Colette (1994) found significant correlations between perceived social support and burden for their sample.

The current sample had lower levels of all categories of caregiving social support than the Lennon, Dean and Martin (1990) study. Only adequacy of instrumental social support was associated with a dependent measure (HADS anxiety). However, adequacy of emotional support did show differences between the three sample groups, with those in the main hospital finding it less adequate.

Other stressors

Overall stress was significantly positively correlated with HADS anxiety, HADS depression, GHQ, and PSOM. The number of stressful events was correlated with PSOM; the mean severity of these events was correlated with HADS anxiety and depression, GHQ and PSOM. Folkman, Chesney, Cooke,

Boccellari and Colette (1994) similarly found negative life events to be significantly correlated with care-giver burden.

Previous experience of HIV

People with more experience of HIV positive deceased friends actually had higher Satisfaction with life scores. This was a surprising finding. A possible explanation is that people who had more experience of HIV related bereavement felt that they were better able to cope with the HIV infection and possible death of their partner. An alternative explanation is that it is a chance finding (and there was no relationship with any of the other dependent variables). Folkman, Chesney, Cooke, Boccellari and Colette (1994) found no relationship between previous loss and care-giver burden.

Relationship quality

Better relationship satisfaction was significantly associated with higher satisfaction with life scores. There was a similar relationship between relationship satisfaction and burden in Folkman, Chesney, Cooke, Boccellari and Colette (1994).

Patients' health

Overall health was significantly correlated with all dependent variables.

Other significant positive correlations with dependent measures included: time since AIDS diagnosis (HADS depression); number of symptoms (HADS anxiety and depression); current amount of time caring (HADS anxiety and

depression, GHQ); and usual amount of time caring (HADS depression). The current study investigated patients at all stages of HIV related disease. There was a trend toward partners of patients with AIDS showing higher levels of HADS anxiety and depression.

Pakenham et al. (1995) did not find an association between patient's number of symptoms or global health rating and partner's psychological distress. However, in the current study the rating of patient's health was done by the partner, suggesting that what is more important in partner's level of distress is not the actual health of the patient, but the partner's perception of their health.

Demographic data

Length of relationship was found to be positively correlated with HADS depression. Perhaps it is more distressing to be facing the illness and possible death of someone with whom you have spent a longer period of time.

4.2 Alternative explanations

Some of the specific alternative explanations for results have already been described in the text above. One explanation for any finding was that of a chance association. Statistical analyses were performed on a large number of variables and five per cent of the time significant findings would be due to chance.

The study was cross-sectional and there is no way of knowing the direction of causality. It is therefore equally possible that psychological distress influences the coping strategy used or the satisfaction with social support, for example, rather than these variables influence psychological distress.

Some items of the COPE may be artefactually correlated with the distress measures. For example apathy and fatigue may be symptoms of depression. If they are endorsed as a coping strategies (disengagement) then this would simply be two different ways of asking the same question. Similarly, high levels of depression may cause people to rate their satisfaction with social support or their perception of the patient's health more negatively, leading to an artefactual correlation between these measures. Beck (1967) described such negative distortion in thought and appraisal that are typical of depressed thinking patterns.

4.3 Methodological considerations

There were a number of methodological considerations that lead to the need for caution when discussing the results. As the design was cross-sectional no conclusions can be drawn regarding direction of causality, only association between the dependent and independent variables. Also there is always the possibility that a third variable may be responsible for the association between variables, although several known moderating factors (for care-giver distress) were included in the study.

The small sample size means that conclusions should be drawn with caution. In addition the sample must be seen as primarily self-selecting nature with the attendant dangers of bias that this brings. In addition the sample consisted almost entirely of white, well-educated participants and thus generalisability of the findings to other groups should not be made. The three sample groups differed significantly on educational attainment of the patient. This perhaps reflects the fact that the sample showing the significantly lower score came from an economically deprived catchment area compared to the main hospital.

As there was no control group there are major limitations to the strength of any conclusions. Findings may have simply been a reflection of being in a gay relationship and not being the partner of a man with HIV infection. A control group of HIV negative men in relationships would clarify this point. Similarly control groups of partners of patients with other illnesses would clarify whether the findings apply uniquely to HIV infection.

Almost all the measures used have been well validated. The GRIMS was being used outside its original purpose and this is reflected by the number of people scoring in the 'undefined' region. There is a need to validate the use of this measure with a gay population.

All measures were self-report and there was no corroboration with observational or third party data. The results may therefore be prone to social desirability factors.

The measure of coping required partners to complete how they 'usually' coped with the patients' infection and illness. This does not allow a fine-grained analysis of coping with specific aspects of the situation, or exploration of changes over time.

4.4 Clinical Implications

The current study confirmed the previous findings that being the partner of someone with HIV infection is associated with higher levels of psychological distress, in particular anxiety. Services for people with HIV infection need to be aware that partners and other people affected by HIV may also be in psychological distress and in need of help.

The current study also showed a significant association between coping strategy and psychological well-being. Until there is resolution of the direction of causality then advice regarding 'adaptive' or helpful coping strategies must be given with caution. Despite this caveat, the following strategies seem likely to be associated with poor coping outcome: behavioural and mental disengagement, focusing/venting emotions and suppression of competing activities. Acceptance is associated with good coping outcome. Coping strategy is amenable to change and can be

influenced by the efforts of the individual and those supporting him. Partners could be given advice (translating the technical language of the COPE) such as:

"Accept that the infection is real and that it has happened. Avoid giving up and switching off when you face your partner's infection and illness. Whilst there is nothing you can do to change the fact of his HIV infection this does not mean that you cannot alter aspects of it. At the same time avoid making his infection the central focus of your life and your relationship. Finally, it seems unhelpful to simply focus on your distress and vent your unhappiness."

4.5 Future research

A major limitation of the current study is its cross-sectional nature. This means that no claims for direction of causation can be made. The Folkman, Chesney, Cooke, Boccellari and Collette (1994) is the initial report from such a longitudinal study but there are limitations in their measures of coping.

There is a need for more detailed research (perhaps utilising qualitative methods) to look in more detail at both coping with specific aspects of the situation and the changes in coping over time. It may be useful to combine the current study's method of measuring coping (how participants usually coped) with that of Folkman, Chesney, Cooke, Boccellari and Collette (1994) who looked at a specific incident of coping. This would overcome the difficulties of using either one in isolation.

Future research is also needed to investigate the generalisability of the current findings to other groups affected by HIV infection (e.g. HIV positive partners, heterosexuals, different ethnic groups).

Including measures of well-being in addition to measures of distress showed significantly different patterns of association, particularly with the satisfaction with life scale (which explored the cognitive aspect of well-being). Future research should also include such measures so that such differences can be explored.

Finally the current study found that coping strategy was significantly associated with levels of psychological distress and well-being. This suggests that future studies investigating moderating variables should include coping strategy in their measures.

5.0 CONCLUSIONS

The major conclusions drawn from this study were:

1. Having a partner with HIV infection was associated with high levels of psychological distress (particularly anxiety). The mean level of anxiety was in the possible clinical disorder range. However, levels of psychological well-being were not significantly lower than community or other sample norms,
2. Coping strategy was an important moderating factor. There was strong evidence to support the importance of coping strategies in predicting level of psychological distress. Acceptance predicted lower psychological distress scores, whilst behavioural disengagement, suppression of competing activities, and focus/venting emotions, predicted higher psychological distress. Mental disengagement was also associated with higher psychological distress although this was not picked out in the regression models. Using a large number of coping strategies was associated with higher anxiety levels although this did not come out in the regression analysis. Suppression of competing activities, behavioural and mental disengagement were associated with lower positive states of mind scores, whilst acceptance was associated with higher scores. Suppression of competing activities predicted lower positive states of mind scores in the regression models.

3. The partner's perception of the patient's overall health predicted level of psychological distress.

4. Other moderating factors also predicted psychological well-being.

Satisfaction with social support predicted higher psychological well-being (both positive states of mind and satisfaction with life). A higher number of other stressful life events predicted lower positive states of mind. Previous experience of HIV related bereavement predicted higher satisfaction with life.

5. These findings are limited by a number of methodological considerations and there is a need for future research with larger more diverse samples, with control groups and of longitudinal design.

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Appendix 1: The questionnaire

QUESTIONNAIRE

Thank you for agreeing to take part in this study. Please now complete the following questionnaire which should take about -- an hour in total. Do not think too long about your responses but rather put down the first idea that comes to you. There may seem to be some repetition in the questions. This is not to catch you out in any way, but is due to using different questionnaires that have been used in other studies.

Feel free to take a break if you get tired. If the questionnaire causes you to think about things which make you distressed then please talk to James now, or contact James Gray or Barbara Hedge on

Remember you are free to stop at any time and there will be no comeback to you or anyone else. Please hand the completed form directly to James or put it in the envelope provided and give it to a member of staff.

Thanks again!

Please give your initials: _____

Please give your date of birth: _____

We would like to know if you have had any medical complaints, and how your health has been in general, **over the past few weeks**. Please answer ALL the questions on the following pages simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you have had in the past.

Please try to answer ALL the questions:
HAVE YOU RECENTLY:

1. Been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
2. Been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
4. Felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
5. Been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
8. Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
9. Had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been getting edgy and bad tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been getting scared and panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
13. Found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
14. Been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

15. Been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual	
16. Been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual	
17. Felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well	
18. Been satisfied with the way you've carried out your tasks?	More Satisfied	About same as usual	Less satisfied than usual	Much less satisfied	--
19. Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful	
20. Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable	
21. Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual	
22. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual	
23. Felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual	
24. Felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual	
25. Thought of the possibility that you might make away with yourself?	Definitely Not	I don't think so	Has crossed my mind	Definitely have	
26. Found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual	
27. Found yourself wishing you were dead and away from it all?	Not at all	No more	Rather more	Much more	
28. Found that the idea of taking your own life kept coming into your mind?	Definitely Not	I don't think so	Has crossed my mind	Definitely has	

The following questions are about the kind of satisfying states of mind that you may have experienced **in the last 7 days**. Please circle one of the scores below the following statements to give a rough estimate of how easy it has been to achieve that particular state of mind:

1. Focused attention: Feeling able to attend to a task you want or need to do, without many distractions from within yourself.

Unable to have it	Trouble in having it	Limited in having it	Have it well
Score: 0	1	2	3

2. Productivity: Feeling of being able to stay at work until a task is finished, do something new to solve problems, or express yourself creatively.

Unable to have it	Trouble in having it	Limited in having it	Have it well
Score: 0	1	2	3

3. Responsible Caretaking: Feeling that you are doing what you should do to take care of yourself or someone else.

Unable to have it	Trouble in having it	Limited in having it	Have it well
Score: 0	1	2	3

4. Restful Repose: Feeling relaxed, without distractions or excessive tension.

Unable to have it	Trouble in having it	Limited in having it	Have it well
Score: 0	1	2	3

5. Sensuous non-sexual pleasure: Being able to enjoy bodily senses, enjoyable intellectual activity, doing things you ordinarily like, such as listening to music, enjoying the outdoors, lounging in a hot bath.

Unable to have it	Trouble in having it	Limited in having it	Have it well
Score: 0	1	2	3

6. Sharing: Being able to commune with others in an empathetic, close way, as in talking, walking, going out, or just being together.

Unable to have it	Trouble in having it	Limited in having it	Have it well
Score: 0	1	2	3

Below are five statements with which you may agree or disagree. Using the 1 to 7 scale below each statement please circle the score which most closely describes how you feel about that statement right now:

1. In most ways my life is close to my ideal.

1	2	3	4	5	6	7
strongly	disagree	slightly	neither	slightly	agree	strongly
disagree		disagree	agree nor	agree		agree
			disagree			

2. The conditions of my life are excellent.

1	2	3	4	5	6	7
strongly	disagree	slightly	neither	slightly	agree	strongly
disagree		disagree	agree nor	agree		agree
			disagree			

3. I am satisfied with my life.

1	2	3	4	5	6	7
strongly	disagree	slightly	neither	slightly	agree	strongly
disagree		disagree	agree nor	agree		agree
			disagree			

4. So far I have attained the important things I want in life.

1	2	3	4	5	6	7
strongly	disagree	slightly	neither	slightly	agree	strongly
disagree		disagree	agree nor	agree		agree
			disagree			

5. If I could live my life over again, I would change almost nothing.

1	2	3	4	5	6	7
strongly	disagree	slightly	neither	slightly	agree	strongly
disagree		disagree	agree nor	agree		agree
			disagree			

We are interested in how people respond to their partner's HIV infection and related illness. There are many ways of dealing with this difficult and stressful situation. This part of the questionnaire asks you to indicate how you have felt and what you have been experiencing over the last month.

Please respond to each of the items on the questionnaire, by circling one number for each, using the response choices listed below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully and make the answers as true for you as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for what you have been doing over the last month, and not what you think 'most people' would say or do. Indicate what you usually did to cope with aspects of your partner's infection or illness.

HOW HAVE YOU RESPONDED TO YOUR PARTNER'S INFECTION OVER THE LAST MONTH?

1	2	3	4
I usually <u>didn't</u> do this <u>at all</u>	I usually did this a <u>little bit</u>	I usually did this <u>a medium amount</u>	I usually did this <u>a lot</u>

- | | 1 | 2 | 3 | 4 |
|--|---|---|---|---------------------|
| | | | | (Please circle one) |
| 1. I tried to grow as a person as a result of the experience. | 1 | 2 | 3 | 4 |
| 2. I turned to work or other substitute activities to take my mind off things. | 1 | 2 | 3 | 4 |
| 3. I got upset and let my emotions out. | 1 | 2 | 3 | 4 |
| 4. I tried to get advice from someone about what to do. | 1 | 2 | 3 | 4 |
| 5. I concentrated my efforts on doing something about it. | 1 | 2 | 3 | 4 |
| 6. I said to myself "this isn't real." | 1 | 2 | 3 | 4 |
| 7. I put my trust in God. | 1 | 2 | 3 | 4 |
| 8. I laughed about the situation. | 1 | 2 | 3 | 4 |
| 9. I admitted to myself that I can't deal with it, and gave up. | 1 | 2 | 3 | 4 |
| 10. I restrained myself from doing anything too quickly. | 1 | 2 | 3 | 4 |
| 11. I discussed my feelings with someone. | 1 | 2 | 3 | 4 |
| 12. I used alcohol or drugs to make myself feel better. | 1 | 2 | 3 | 4 |
| 13. I got used to the idea that it happened. | 1 | 2 | 3 | 4 |
| 14. I talked to someone to find out more about the situation. | 1 | 2 | 3 | 4 |
| 15. I kept myself from getting distracted by other thoughts or activities. | 1 | 2 | 3 | 4 |
| 16. I daydreamed about things other than this. | 1 | 2 | 3 | 4 |
| 17. I got upset, and was really aware of it. | 1 | 2 | 3 | 4 |
| 18. I sought God's help. | 1 | 2 | 3 | 4 |
| 19. I made a plan of action. | 1 | 2 | 3 | 4 |
| 20. I made jokes about it. | 1 | 2 | 3 | 4 |
| 21. I accepted that this has happened and that it can't be changed. | 1 | 2 | 3 | 4 |
| 22. I held off doing anything about it until the situation permits. | 1 | 2 | 3 | 4 |
| 23. I tried to get emotional support from friends or relatives. | 1 | 2 | 3 | 4 |
| 24. I just gave up trying to reach my goal. | 1 | 2 | 3 | 4 |
| 25. I took additional action to try to get rid of the problem. | 1 | 2 | 3 | 4 |

Please read each item and place a tick in the box opposite the reply that comes closest to how you have been feeling in the **past month**: Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense/"wound-up"

Most of the time ...
A lot of the time ...
Occasionally ...
Not at all ...

I still enjoy the things I used to:

Definitely as much ...
Not quite as much ...
Only a little ...
Hardly at all ...

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly ...
Not too badly ...
Little, doesn't worry me ...
Not at all ...

I can laugh and see the funny side of things:

As much as I ever could ...
Not quite as much now ...
Definitely not so much ...
Not at all ...

Worrying thoughts go through my mind:

A great deal of the time ...
A lot of the time ...
From time to time ...
Only occasionally ...

I feel cheerful:

Not at all ...
Not often ...
Sometimes ...
Most of the time ...

I can sit at ease and feel relaxed:

Definitely ...
Usually ...
Not often ...
Not at all ...

I feel as if I am slowed down:

Nearly all the of the time ...
Very often ...
Sometimes ...
Not at all ...

I get a frightened feeling like 'butterflies' in my stomach:

Not at all ...
Occasionally ...
Quite often ...
Very often ...

I have lost interest in my appearance:

Definitely ...
I don't take as much care as I should ...
I may not take quite as much care ...
I take just as much care as ever ...

I feel restless as if I have to be on the move:

Very much indeed ...
Quite a lot ...
Not very much ...
Not at all ...

I look forward with enjoyment to things:

As much as I ever did ...
Rather less than I used to ...
Definitely less than I used to ...
Hardly at all ...

I get sudden feelings of panic:

Very often indeed ...
Quite often ...
Not very often ...
Not at all ...

I can enjoy a good book, radio or TV programme:

Often ...
Sometimes ...
Not often ...
Very seldom ...

We would like to know if you have had any medical complaints, and how your health has been in general, **over the past few weeks**. Please answer **ALL** the questions on the following pages simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you have had in the past.

Please try to answer **ALL** the questions:
HAVE YOU RECENTLY:

1. Been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
2. Been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
4. Felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
5. Been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. Been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
8. Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
9. Had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been getting edgy and bad tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. Been getting scared and panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
13. Found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
14. Been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

15. Been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
16. Been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
17. Felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
18. Been satisfied with the way you've carried out your tasks?	More Satisfied	About same as usual	Less satisfied than usual	Much less satisfied
19. Felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
20. Felt capable of making decisions about thing?	More so than usual	Same as usual	Less so than usual	Much less capable
21. Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
22. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
23. Felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
24. Felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
25. Thought of the possibility that you might make away with yourself?	Definitely Not	I don't think so	Has crossed my mind	Definitely have
26. Found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
27. Found yourself wishing you were dead and away from it all?	Not at all	No more	Rather more	Much more
28. Found that the idea of taking your own life kept coming into your mind?	Definitely Not	I don't think so	Has crossed my mind	Definitely has

The following questions are about the kind of satisfying states of mind that you may have experienced **in the last 7 days**. Please circle one of the scores below the following statements to give a rough estimate of how easy it has been to achieve that particular state of mind:

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4. Restful Repose: Feeling relaxed, without distractions or excessive tension.

Unable to have it	Trouble in having it	Limited in having it	Have it well
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5. Sensuous non-sexual pleasure: Being able to enjoy bodily senses, enjoyable intellectual activity, doing things you ordinarily like, such as listening to music, enjoying the outdoors, lounging in a hot bath.

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6. Sharing: Being able to commune with others in an empathetic, close way, as in talking, walking, going out, or just being together.

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Below are five statements with which you may agree or disagree. Using the 1 to 7 scale below each statement please circle the score which most closely describes how you feel about that statement right now:

1. In most ways my life is close to my ideal.

1	2	3	4	5	6	7
strongly disagree	disagree	slightly disagree	neither agree nor disagree	slightly agree	agree	strongly agree

2. The conditions of my life are excellent.

1	2	3	4	5	6	7
strongly disagree	disagree	slightly disagree	neither agree nor disagree	slightly agree	agree	strongly agree

3. I am satisfied with my life.

1	2	3	4	5	6	7
strongly disagree	disagree	slightly disagree	neither agree nor disagree	slightly agree	agree	strongly agree

4. So far I have attained the important things I want in life.

1	2	3	4	5	6	7
strongly disagree	disagree	slightly disagree	neither agree nor disagree	slightly agree	agree	strongly agree

5. If I could live my life over again, I would change almost nothing.

1	2	3	4	5	6	7
strongly disagree	disagree	slightly disagree	neither agree nor disagree	slightly agree	agree	strongly agree

We are interested in how people respond to their partner's HIV infection and related illness. There are many ways of dealing with this difficult and stressful situation. This part of the questionnaire asks you to indicate how you have felt and what you have been experiencing over the last month.

Please respond to each of the items on the questionnaire, by circling one number for each, using the response choices listed below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully and make the answers as true for you as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for what you have been doing over the last month, and not what you think 'most people' would say or do. Indicate what you usually did to cope with aspects of your partner's infection or illness.

HOW HAVE YOU RESPONDED TO YOUR PARTNER'S INFECTION OVER THE LAST MONTH?

1	2	3	4
I usually <u>didn't</u> do this <u>at all</u>	I usually did this a <u>little bit</u>	I usually did this <u>a medium amount</u>	I usually did this <u>a lot</u>

- | | | | | |
|--|---------------------|---|---|---|
| | (Please circle one) | | | |
| 1. I tried to grow as a person as a result of the experience. | 1 | 2 | 3 | 4 |
| 2. I turned to work or other substitute activities to take my mind off things. | 1 | 2 | 3 | 4 |
| 3. I got upset and let my emotions out. | 1 | 2 | 3 | 4 |
| 4. I tried to get advice from someone about what to do. | 1 | 2 | 3 | 4 |
| 5. I concentrated my efforts on doing something about it. | 1 | 2 | 3 | 4 |
| 6. I said to myself "this isn't real." | 1 | 2 | 3 | 4 |
| 7. I put my trust in God. | 1 | 2 | 3 | 4 |
| 8. I laughed about the situation. | 1 | 2 | 3 | 4 |
| 9. I admitted to myself that I can't deal with it, and gave up. | 1 | 2 | 3 | 4 |
| 10. I restrained myself from doing anything too quickly. | 1 | 2 | 3 | 4 |
| 11. I discussed my feelings with someone. | 1 | 2 | 3 | 4 |
| 12. I used alcohol or drugs to make myself feel better. | 1 | 2 | 3 | 4 |
| 13. I got used to the idea that it happened. | 1 | 2 | 3 | 4 |
| 14. I talked to someone to find out more about the situation. | 1 | 2 | 3 | 4 |
| 15. I kept myself from getting distracted by other thoughts or activities. | 1 | 2 | 3 | 4 |
| 16. I daydreamed about things other than this. | 1 | 2 | 3 | 4 |
| 17. I got upset, and was really aware of it. | 1 | 2 | 3 | 4 |
| 18. I sought God's help. | 1 | 2 | 3 | 4 |
| 19. I made a plan of action. | 1 | 2 | 3 | 4 |
| 20. I made jokes about it. | 1 | 2 | 3 | 4 |
| 21. I accepted that this has happened and that it can't be changed. | 1 | 2 | 3 | 4 |
| 22. I held off doing anything about it until the situation permits. | 1 | 2 | 3 | 4 |
| 23. I tried to get emotional support from friends or relatives. | 1 | 2 | 3 | 4 |
| 24. I just gave up trying to reach my goal. | 1 | 2 | 3 | 4 |
| 25. I took additional action to try to get rid of the problem. | 1 | 2 | 3 | 4 |

- | | | |
|--|-----|-------|
| 30. The health of someone you know who is HIV positive is deteriorating. | YES | _____ |
| 31. You have felt that your own health may be deteriorating. | YES | _____ |
| 32. Your doctor has told you that your health is deteriorating. | YES | _____ |
| 33. You thought you were HIV positive. | YES | _____ |
| 34. Someone suggested to you that you may be HIV positive. | YES | _____ |

Please add any other events to this list that you feel may have contributed to your stress in the last six months. Be as specific as you want in describing these events and don't forget to indicate using the 1-10 scale above how stressful that event was for you.

EVENT	Experienced	Stress score (1-10)
1.	YES	_____
2.	YES	_____
3.	YES	_____
4.		
5.		
6.		
7...		

Please complete this part of the questionnaire to describe your current relationship with your partner. Circle the number that best corresponds to your feelings regarding each statement.

1 strongly disagree	2 disagree	3 agree	4 strongly agree	
1. My partner is usually sensitive to and aware of my needs.	1	2	3	4
2. I really appreciate my partner's sense of humour.	1	2	3	4
3. My partner doesn't seem to listen to me any more.	1	2	3	4
4. My partner has never been disloyal to me.	1	2	3	4
5. I would be willing to give up my friends if it meant saving our relationship.	1	2	3	4
6. I am dissatisfied with our relationship.	1	2	3	4
7. I wish my partner was not so lazy and didn't keep putting things off.	1	2	3	4
8. I sometimes feel lonely even when I am with my partner.	1	2	3	4
9. If my partner left me life would not be worth living.	1	2	3	4
10. We can 'agree to disagree' with each other.	1	2	3	4
11. It is useless carrying on with a relationship beyond a certain point.	1	2	3	4
12. We both seem to like the same things.	1	2	3	4
13. I find it difficult to show my partner that I am feeling affectionate.	1	2	3	4
14. I never have second thoughts about our relationship.	1	2	3	4
15. I enjoy just sitting and talking with my partner.	1	2	3	4
16. I find the idea of spending the rest of my life with my partner rather boring.	1	2	3	4
17. There is always plenty of 'give and take' in our relationship.	1	2	3	4
18. We become competitive when we have to make decisions.	1	2	3	4
19. I no longer feel I can really trust my partner.	1	2	3	4
20. Our relationship is still full of joy and excitement.	1	2	3	4
21. One of us is continually talking and the other is usually silent.	1	2	3	4
22. Our relationship is continually evolving.	1	2	3	4
23. Committed relationships are really more about security and money, than about love.	1	2	3	4
24. I wish there was more warmth and affection between us.	1	2	3	4
25. I am totally committed to my relationship with my partner.	1	2	3	4
26. Our relationship is sometimes strained because my partner is always correcting me.	1	2	3	4
27. I suspect that we may be on the brink of seperation.	1	2	3	4
28. We can always make up quickly after an argument.	1	2	3	4

The following questions relate to previous experience to HIV related disease or bereavement.

1. Have you had a previous partner (someone you have had a committed relationship for at least six months) who has been infected with HIV?

YES / NO.
(please delete as appropriate)

If yes, then please give number
of people that you have known:

2. Have you had a previous partner who has died through HIV related disease?

YES / NO.
(please delete as appropriate)

If yes, then please give number
of people that you have known:

3. Have you had any friends who have been infected with HIV?

YES / NO.
(please delete as appropriate)

If yes, then please give number
of people that you have known:

4. Have you had any friends who have died through HIV related disease?

YES / NO.
(please delete as appropriate)

If yes, then please give number
of people that you have known:

5. Have you any family members who have been infected with HIV?

YES / NO.
(please delete as appropriate)

If yes, then please give number
of people that you have known:

6. Have you any family members who have died through HIV related disease?

YES / NO.
(please delete as appropriate)

If yes, then please give number
of people that you have known:

YOU

Age:

Education: Schooling till 16 or younger (O'level or equivalent) /
(please Schooling till 18 (A'level or equivalent) /
circle one) Further Education at College /
 Further Education at Polytechnic or University /
 Post-graduate education (masters or doctoral level)

Ethnic Background:
(how you would describe yourself)

In general would you say your health is: excellent / very good / good / fair / poor / very poor

Please give the approximate number of days off work
or unable to function, over the last year due to your own sickness:

Please give any current illness or health problems:

.....

.....
HIV sero-status if known: HIV positive / HIV negative
 not tested but assume positive / not tested assume negative
 no idea and never tested.

YOUR RELATIONSHIP

Length of relationship:

Do you live together / share a home? YES / NO

If Yes, does anyone else live there? YES / NO

If Yes, please give number of people
and their relationship with yourself:

YOUR PARTNER

Age:

Education: Schooling till 16 or younger (O'level or equivalent) /
(please Schooling till 18 (A'level or equivalent) /
circle one) Further Education at College /
 Further Education at Polytechnic or University /
 Post-graduate education (masters or doctoral level)

Ethnic Background:
(how your partner would describe himself)

In general would you say his health was: excellent / very good / good / fair / poor / very poor
Diagnosis: Asymptomatic HIV infection/
Symptomatic, but not AIDS defining HIV infection/
An AIDS defining condition

Please list any HIV related symptoms:

.....

.....

Length of time since HIV infection diagnosis:(years/months)

Length of time of your own knowledge of your partner's
HIV infection diagnosis:(years/months)

Length of time since symptomatic HIV diagnosis:(years/months)

Length of time of your own knowledge of your partner's
symptomatic HIV diagnosis:(years/months)

Length of time since AIDS diagnosis:(years/months)

Length of time of your own knowledge of your partner's
AIDS diagnosis:(years/months)

Do you know what his latest CD4 count is?

Does he use any of the following?: AZT
..... ddI or ddC
..... other trial drugs
... Septrin
..... Hickman Line
..... Portocath

Amount of time spent looking after partner over last week:
None / up to 1 hour a day / 1 to 2 hours a day / 3 to 4 hours a day / 4 to 8 hours a day /
8 to 12 hours per day / 12 to 16 hours a day / 16 to 24 hours a day

Usual amount of time spent looking after partner (e.g. over the last month):
None / up to 1 hour a day / 1 to 2 hours a day / 3 to 4 hours a day / 4 to 8 hours a day /
8 to 12 hours per day / 12 to 16 hours a day / 16 to 24 hours a day

Do you provide any of the following for your partner:
help with mobility
help with eating
help with bathing
help with going to the toilet
emotional support
financial support

Are you having any current problems in providing any help for your partner?:

.....

.....

.....

What services does your partner currently receive:

- doctor
- health adviser
- home support team
- social worker
- counsellor
- psychologist
- other:

Does he receive services from any of the following voluntary organisations?:

- Terence Higgins Trust
- Lighthouse
- Mildmay
- Body Positive
- Other:

Are there any service(s) that your partner would like, that he is currently not getting?:

.....

.....

.....

.....

.....

.....

YOU

What services do you currently receive:

- doctor
- health adviser
- home support team
- social worker
- counsellor
- psychologist
- other:

Do you receive services from any of the following voluntary organisations?:

Terence Higgins Trust

Lighthouse

Mildmay

Body Positive

Other:

Are there any service(s) that you would like, that you are currently not getting?:

.....

.....

.....

.....

.....

.....

Thank you very much for taking the time to fill out this questionnaire. Remember now to either give it to James Gray or put it in the envelope provided. If completing the questionnaire has proved distressing and you would like to talk to someone, then please do not hesitate to get in contact with **James or Barbara** on

If you would like a copy of the results of this study then please give below your name and the address to send them to:

Appendix 2: Ethical approval and correspondence

1.4 Title of Project: "Psychological well-being and coping in the partners of gay men with HIV-related disease."

1.5 Background of project:

The impact of HIV on individuals has been the focus of much research. Their families and partners have recently begun to be investigated in their own right (e.g. McCann and Wadsworth, 1992, Raveis and Siegel, 1991, Folkman et al. 1994a, 1994b). These studies have shown that coping with disease and disability in a partner is difficult for anyone, but with gay men there are added pressures. These include: the disease characteristics (HIV related infection is unpredictable); carer characteristics (typically a young male partner who would not expect to be caring at this stage in life); wider social considerations (there may be a need to conceal the relationship to avoid problems at work or with families); the fact that the partner may be at risk of infection.

People use different ways of coping with difficult situations. They may actively attempt to solve the problem, they may look for help from friends or family, they may deny there is a problem etc. There is already quite a large literature on coping looking at different medical populations (see for example Lazarus 1993). Such studies have found that some ways of coping are more effective than others and this is likely to be true when faced with a partner with HIV. This study is an investigation into such effective coping strategies.

The aims of this study therefore are to find out whether a particular coping style or pattern of coping styles is more effective when faced with a partner with HIV related illness. This would enable advice on effective coping to be given to partners, who may play a very important role in the care and well-being of people with HIV related disease. It may also allow for the identification of people at risk of not coping, and help with prevention, and targetting of psychological help.

A number of other factors have to be looked at in addition to the coping style. For example people may be more distressed not because they are using a particular way of coping but because they are faced with a very ill partner. In this case the health of the partner may be responsible for both the level of distress and the coping pattern. It is therefore necessary to investigate other significant factors so that coping style can be shown to have an important function to play over and above the influence of these factors. Investigating these factors allows us to investigate their own independent influence which leads to the aims three to seven outlined below.

1.6 Aims of Project:

The specific aims of the project are to investigate the following hypotheses:

1. That psychological well-being will be related to the number of adaptive coping strategies used (both emotion and problem focused) and not the type - that people who use both types will be coping better than those who use only one.

2. That there will be a relationship between the index patient's disease stage and the partner's well being (that they will be more distressed at a more advanced stage of disease).

3. That there will be a relationship between the partner's own health and psychological well-being (that those with poorer health will have poorer psychological well-being).

4. That those with perceived adequate social support will have better psychological well-being than those with inadequate social support.

5. That those with higher quality relationships with their partner will have lower psychological distress.

6. That the higher the number of stressful life events and daily hassles, the higher the psychological distress.

7. That the experience of previous bereavement with HIV will be

related to higher levels of psychological distress.

8. That coping style will explain a significant amount of psychological distress, when compared with other factors such as number of stressful life events.

1.7 Method/Design of Project

Participants will be about 50 partners (healthy volunteers) of gay men with HIV related illness who are patients of the NHS Trust. Partners are defined as people in a committed relationship for at least six months. Recruitment will be by posters or a direct approach from the principal investigator, following discussion with health care workers. The partners will be given an information sheet and a consent form (see below). If consent is given they will be provided with a questionnaire to complete. The questionnaire contains:

- a) Measures of psychological well-being (both positive and negative):
 - i) the Hospital Anxiety and Depression scale (Hamilton et al. 1983),
 - ii) The General Health Questionnaire - GHQ 28),
 - iii) Positive States of Mind Scale (Horowitz et al. 1988),
 - iv) The satisfaction with life scale (Deiner et al. 1985);
- b) A measure of coping style: The COPE (Carver et al. 1989);
- c) Measures of other factors that might explain the level of well-being:
 - i) The short form social support questionnaire (Sarason et al. 1987);
 - ii) A specific social support questionnaire related to caretaking (after Lennon et al. 1990);
 - iii) A 'life events' scale based on Nott and Vedhara, 1995.
 - iv) The quality of the relationship (using an adapted version of the Golombok-Rust Inventory of Marital State, Rust et al. 1989);
 - v) Previous exposure to HIV related disease or bereavement;
 - vi) Background factors including: length of relationship; health of index patient; length of time since diagnosis; length of time since partner knew of the diagnosis; amount of time spent caretaking for partner; own health status; biographical details including age, ethnic background, education, contact with services, etc.

These last factors (section c above) are important as we will be able to investigate whether coping style is having a significant effect or whether any variation in psychological well-being is due to other things such as having a very ill partner, or being socially isolated.

If partners decline to take part in the study then no further contact will be initiated. All subjects will receive exactly the same questionnaire which should take no more than an hour to complete. Questionnaires can either be completed there and then, or taken home. Initials and dates of birth will be recorded on a detachable sheet on the questionnaire and as soon as possible a research code will be given to the completed questionnaire. The research code sheet will be kept separately to the completed questionnaires and both will be locked securely in the psychology offices attached to the

1.8 Duration of project

Data collection (following ethical approval) to be from October 1995 to March 1996.

1.9 Justification of Sample Size

Quantitative analysis will include correlations, chi-square, t-test, ANOVA and multiple regression. With a sample size >50 then this should provide adequately large subgroups (n>5) for the appropriate analyses.

1.10 Multi-centred study?

The study will take place within the

NHS Trust

2. Discomfort and Potential Hazards for Subjects

2.1 Is participation in the research of potential benefit to subjects who are patients? YES/NO

If I observe partners who appear unusually or significantly distressed then, with the individuals permission, I will inform the clinical service.

Reflecting and having a chance to think about one's situation may help the partner to come to a new perspective with possible benefits for the index patient.

On completion of the research there is the benefit that being better informed about coping may lead to higher psychological well-being in the partner and thus more resources available for caring and support of the index patient.

2.2 Describe any potential discomforts to the patient/healthy volunteer in the research.

In the unlikely event that completing the questionnaire may prove distressing in itself (although note that there is no pressure to participate in the study), there will be the opportunity to discuss feelings with the principal investigator (in a one off session). At that time if there is felt to be the need for more support then information will be available regarding other sources of help, or referral to the psychology waiting list. The offer of a chance to talk will be made verbally and included in written form on the questionnaire. If the person appears visibly distressed during the study they will also be verbally offered a session.

2.3 Aside from discomfort, describe potential hazards which may be suffered by the patients/healthy volunteers.

See above.

2.4 Outline the degree to which these risks are balanced against the potential benefits to the patients/healthy volunteers involved or to patients/people in general.

I feel that the risk of distress from the questionnaire is minimal and that the moves outlined above are potentially adequate to safely contain such distress.

2.5 If patients are in a clinical trial, will they be denied a standard treatment for their condition?

N/A.

2.6 When two or more methods of treatment are being compared, what criteria will be employed for deciding the end point ...

N/A.

2.7 What monitoring mechanisms will be in place to decide when patients/healthy volunteers should be withdrawn from the research.

If the questionnaire is completed there and then, there will be the opportunity to observe emotional state. In the event of significant distress then it will be suggested that they withdraw from the study.

2.8 What procedures and subsequent observations are to be made on patients/healthy volunteers for the purpose of detecting any complications arising from the investigation?

As above.

2.9 Are there any other invasive procedures associated with the research which you have not mentioned - e.g. biopsies, endoscopies, pacings and washouts? YES/NO

2.10 Will the GP (or works medical officer) of the patient/healthy volunteer be notified? YES/NO.

Given the subject group this may well be felt by them to be inappropriate e.g. the relationship or sexual orientation may well be concealed from the GP.

2.11 If subjects are healthy volunteers, do they have any previous or existing professional relationship with the investigator? YES/NO

3. Payment/Finance

There will be no payment to the subjects, or gained by the researchers and so this section is N/A.

4. Radiation

No radiation is involved in this study, therefore N/A.

5. Drugs employed in the investigation

No drugs are involved in this study, therefore N/A.

6. Insurance

Indemnity for James Gray is provided through his contract of employment with Oxford Health Authority, and an Honorary contract with the

NHS Trust. Dr. Hedge is covered within her contract and all relevant psychology or general managers will be informed.

7. Confidentiality

7.1 Will your research include named subjects, subjects whose names have been separately coded or un-named subjects?

Subjects whose initials and dates of birth will have been separately coded via a code number known only to James Gray.

7.2 Where will locked files of research materials be stored?

In locked filing cabinets in the psychology offices at Hospital.

7.3 If the research involves storage of computerised data, which might enable the subject to be identified, please indicate the person in charge of computer systems security for your research site.

The computerised data will not permit identification due to the use of research codes stored separately.

7.4 Does the research and any subsequent publications entail the use of photographs or video? YES/NO.

7.5 If research involves only access to medical records, will consent from patients be obtained? YES/NO - N/A

8. Consent

8.1 Please read the Appendix concerning consent before proceeding.

8.2 What type of consent will you seek? Written/verbal only.

8.3 By whom will consent be sought? (b) below

a) The Consultant/Investigator responsible for the research.

Name:

b) Another Clinician/Investigator actively conducting the research.

Name: **James Gray**

c) Any other Clinician/Investigator

Names:

8.4 How and where will the researcher make contact with the patient/healthy volunteer for the purposes of giving consent? (In the case of patients, this should ordinarily be done through the Clinician most active in the patient's treatment.)

Contact will be made with potential subjects by a poster requesting volunteers,

or by direct approach from James Gray (politely, neutrally and non-coercively), following discussion with involved health care workers.

This will take place at In- or out-patient services for people with HIV in the NHS Trust.

8.5 If the research involves patients who have been detained under the Mental Health Act, how will you decide which subjects are and are not able to give informed consent for the participation?

N/A.

8.6 If your research proposal involves incompetent patients above the age of 16, you should as a matter of courtesy provide an information sheet for relatives.

N/A.

8.7 - 8.12 Please see relevant information sheet and consent form (attached as separate document).

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Lennon, M.C., Martin, J.L., & Dean L. (1990). The influence of social support on AIDS related grief reaction among gay men. Soc. Sci. Med., 31.4, 477-484,

McCann, K. & Wadsworth, E. (1992). The role of informal carers in supporting gay men who have HIV related disease: what do they do and what are their needs? AIDS Care, 4, 25-34.

Raveis, V.H. & Seigel, K. (1991). The impact of caregiving on informal or familial caregivers. AIDS Patient Care, Feb 1991, 39-43.

ALL CORRESPONDENCE TO BE ADDRESSED TO:

MR MARK KENDALL
ELCHA RESEARCH ETHICS COMMITTEE
61 PHILPOT STREET
WHITECHAPEL
LONDON, E1 2JH
TEL: 071-377-7325



Dr Barbara Hedge

Chairman
Professor Frances Heidensohn

Our ref: MK/ash

3 October 1995

Dear Dr Hedge

Re: P/95/312 - "Psychological well-being and coping in the partners of gay men with HIV related disease".

I am happy to inform you that the above study has been approved by the Chairman as ethically satisfactory and will be ratified in a future meeting.

I should be grateful if you would inform all concerned with the study of the above decision.

Your application has been approved on the understanding that you comply with Good Clinical Practice and that all raw data is retained and available for inspection for fifteen years.

Please note the following conditions to the approval:

1. The Committee's approval is for the length of time specified in your application. If you expect your project to take longer to complete (i.e. collection of data), a letter from the principal investigator to the chairman will be required to further extend the research. This will help the Committee to maintain comprehensive records.
2. Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee or Chairman's approval.
3. The Committee should be notified immediately of any serious adverse events or if the study is terminated prematurely.
4. You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, such as extra work for laboratories.
5. You must ensure that where appropriate, nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.
6. Patients and volunteers taking part in the study should be informed of the outcome of the trial and where appropriate, the reasons for its termination.

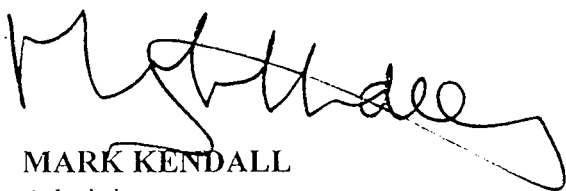
ALL CORRESPONDENCE TO BE ADDRESSED TO:

MR MARK KENDALL
ELCHA RESEARCH ETHICS COMMITTEE
61 PHILPOT STREET
WHITECHAPEL
LONDON, E1 2JH
TEL: 071-377-7325

7. The Committee should be sent one copy of any publications arising from your study, or a summary if there is to be no publication.

Please quote the above study number in any future related correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Mark Kendall', written over a horizontal line.

MARK KENDALL
Administrator
ELCHA Research Ethics Committee

cc. Mr James Gray



London
Lighthouse

*A centre for people facing
the challenge of AIDS*

20 March 1996

James Grey
Clinical Psychologist in training

111-117 Lancaster Road
London W11 1QT

Tel 0171-792 1200

Fax 0171-229 1258

Minicomms:

0171-792 2979 (Reception)

0171-229 6062 (Residential Unit)

Dear James Grey

As requested, I am writing to confirm in writing that London Lighthouse's Ethics Advisory Sub-committee has approved your request for approval to advertise your research study in the Centre.

I hope that your study is progressing well.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Judy Wolfram', with a stylized flourish at the end.

Judy Wolfram
Assistant Director, Operational Services



London Lighthouse Ltd
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Registered company no 2043745
Registered in England
Registered office as above

Appendix 3: Invitations to participate and posters

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Dr. Barbara Hedge and James Gray (Clinical Psychology Services) invite you to participate in a research project which we believe to be of potential importance. In order to help you understand what the research is about, we are providing you with the following information which we want to be sure you understand before you formally agree to participate. Be sure to ask any questions you have about the information which follows and we will do our best to explain and to provide any further information you require.

This research project looks at the way in which partners of gay men with HIV-related disease cope with the difficulties they may be faced with. The study has the full support of

The purpose of the research is to find out whether some ways of coping are better than others. We would then be able to offer sound advice to people who may be having trouble. We may also be able to identify people who are likely to have more problems and be able to offer them extra support. The research involves completing a questionnaire looking at coping patterns, psychological well-being and other things such as social support.

If you decide to participate you will be given a questionnaire to complete. This should take less than an hour. You can either complete it here now or we can arrange a convenient time.

If you do take part, you might find that completing the questionnaire helps you to reflect and clarify what you are thinking and feeling. However, it is possible that this may make you feel distressed. If you find this and would like to talk to someone about how things are going, then please speak to James, or get in contact at the address below.

Your completed questionnaire will be seen only by James or Barbara, and confidentiality and anonymity will be protected. If you would like any further information please feel free to speak to James or Barbara. This study is being undertaken as part of James's training in Clinical Psychology. Dr. Barbara Hedge is his supervisor for this research project.

You are free not to participate and may withdraw from the project at any time. This will not jeopardise your, or anyone else's, treatment in any way. General information on your rights, particularly as regards participation in research studies may also be obtained from your local Community Health Council.

Dr. Barbara Hedge
Consultant Clinical Psychologist

James Gray
Trainee Clinical Psychologist

INVITATION TO TAKE PART IN A RESEARCH PROJECT

The Clinical Psychology Service at . is
currently doing research into how **partners of gay men**
with HIV cope with the difficulties that they may be facing.

This will involve completing a questionnaire (it takes about
half an hour).

If you are interested in taking part, please contact:

James Gray (Trainee Clinical Psychologist)

Tel.:
(or within ext.)

ARE YOU HIV-POSITIVE AND A GAY
MAN?

DO YOU HAVE A PARTNER?

The Clinical Psychology Service at _____ would like to involve your partner in a research project looking at how he is coping and what sort of difficulties he may be facing. This involves completing a questionnaire which takes about half an hour.

Please pick up a leaflet from reception and show it to your partner!

**VOLUNTEERS
NEEDED**

The clinical psychology department at [redacted] is
doing research looking at partners
of men with HIV.

If you are interested in taking part, which
includes filling out a questionnaire

please contact James Gray on
[redacted]

Appendix 4: Consent form

WRITTEN CONSENT FORM

I have read the attached information on the research in which I have been asked to participate and have been given a copy to keep. I have had the opportunity to discuss the details and ask questions about this information.

The investigator has explained the nature and purpose of the research and I believe that I understand what is being proposed. For example, I understand that this trial is part of a research project designed to promote medical knowledge, and that it has been approved by the East London and City Health Authority Research Ethics Committee.

I have been informed that the proposed study involves filling out a questionnaire that has been fully explained to me, together with possible risk involved.

I understand that my personal involvement and my particular data from this study will remain strictly confidential. Only researchers involved in the study will have access to the completed questionnaire.

I hereby fully and freely consent to participate in this study, which has been fully explained to me.

VOLUNTEER'S INITIALS:

VOLUNTEER'S SIGNATURE:

VOLUNTEER'S WITNESS'S NAME:

VOLUNTEER'S WITNESS'S SIGNATURE:.....

INVESTIGATOR'S NAME:

INVESTIGATOR'S SIGNATURE:

DATE:

The following should be signed by the clinician/investigator responsible for obtaining consent.

As the Investigator responsible for this research or a designated deputy, I confirm that I have explained to the volunteer named above the nature and purpose of the research to be undertaken.

INVESTIGATOR'S NAME:

INVESTIGATOR'S SIGNATURE:.....

DATE:

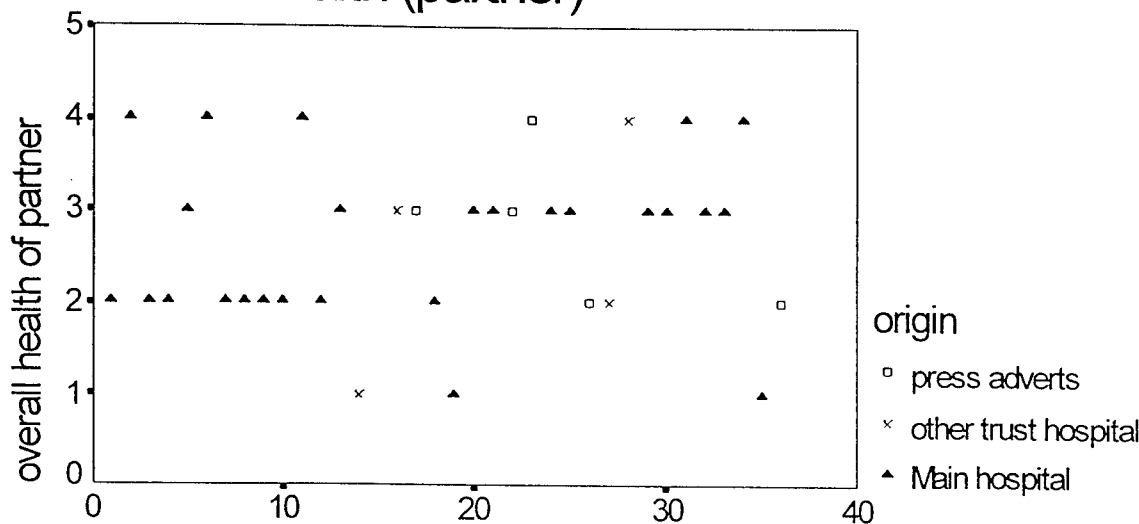
Subjects are warned not to take part in more than one investigation at any time.(e.g. to avoid medication interactions)

If you are at all concerned about this study, would like further information, or feel any distress please contact:

James Gray or Dr. Barbara Hedge
Tel.:

Appendix 5: Examples of scatter plots

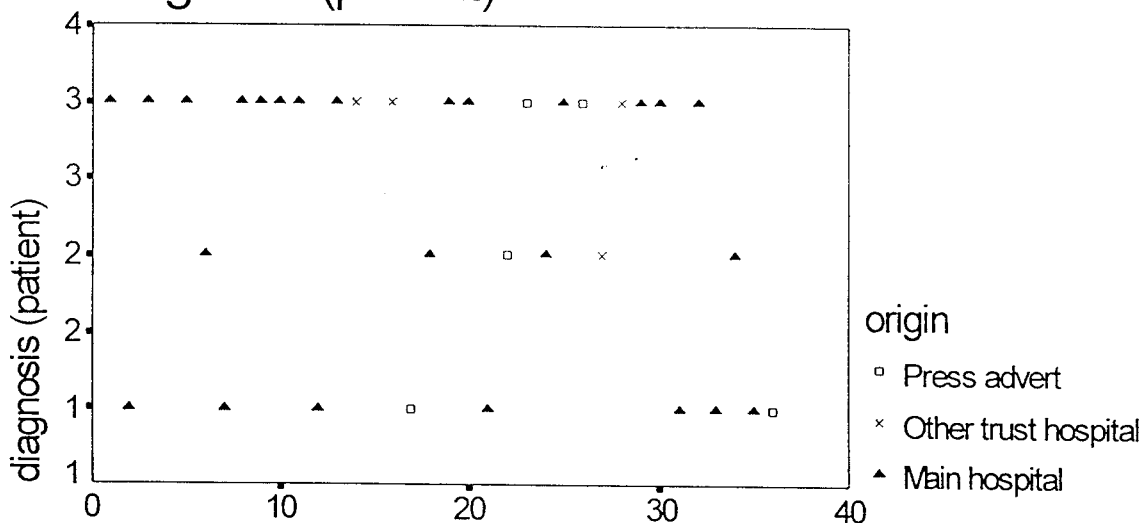
Overall health (partner)



CASE

Where: 1= excellent, 5 = poor

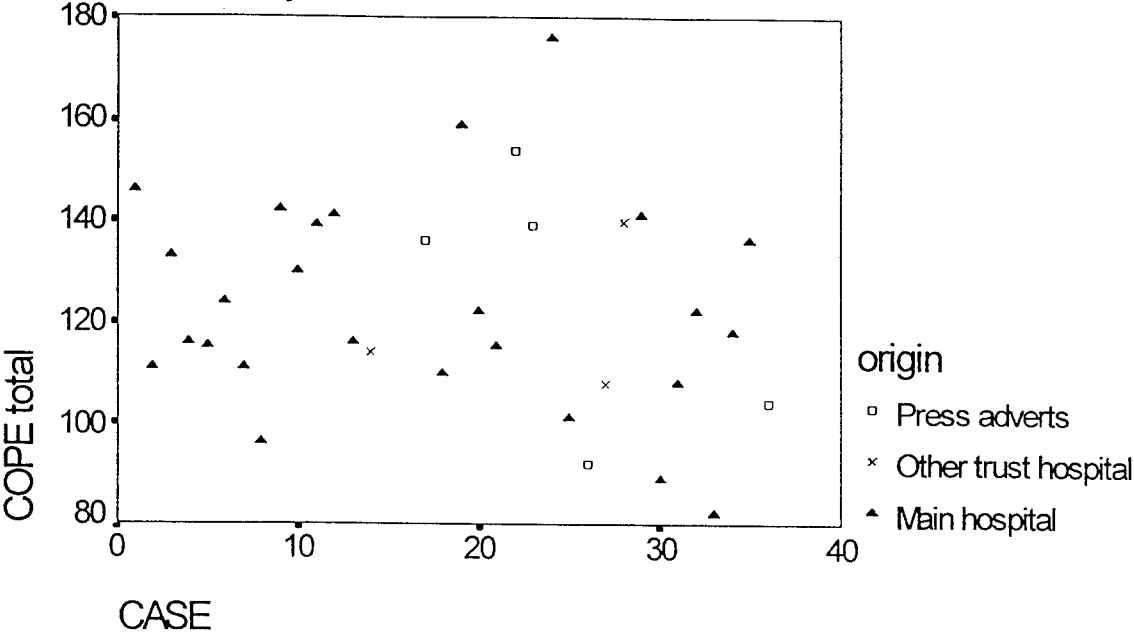
Diagnosis (patient)



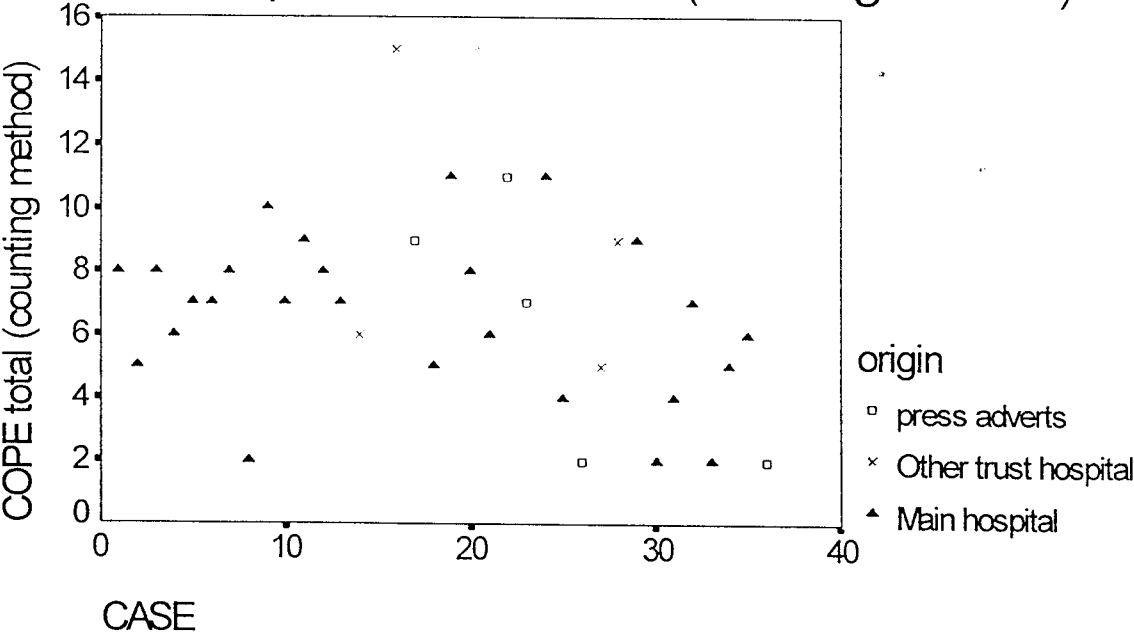
CASE

1= asymptomatic, 2= symptomatic, 3= AIDS

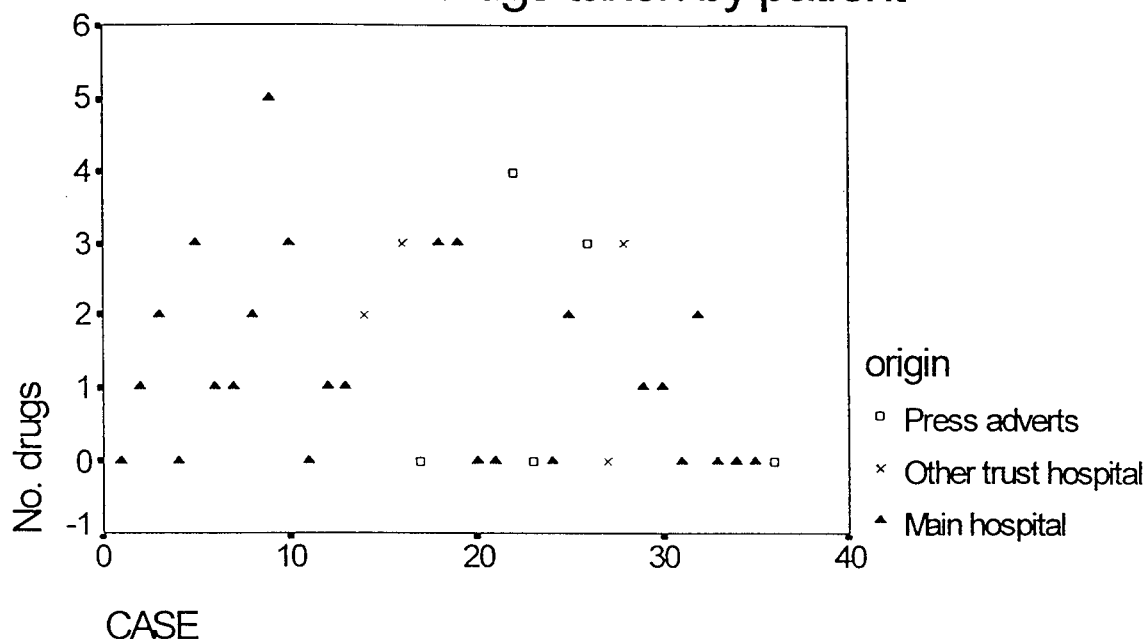
Scatter plot for COPE total



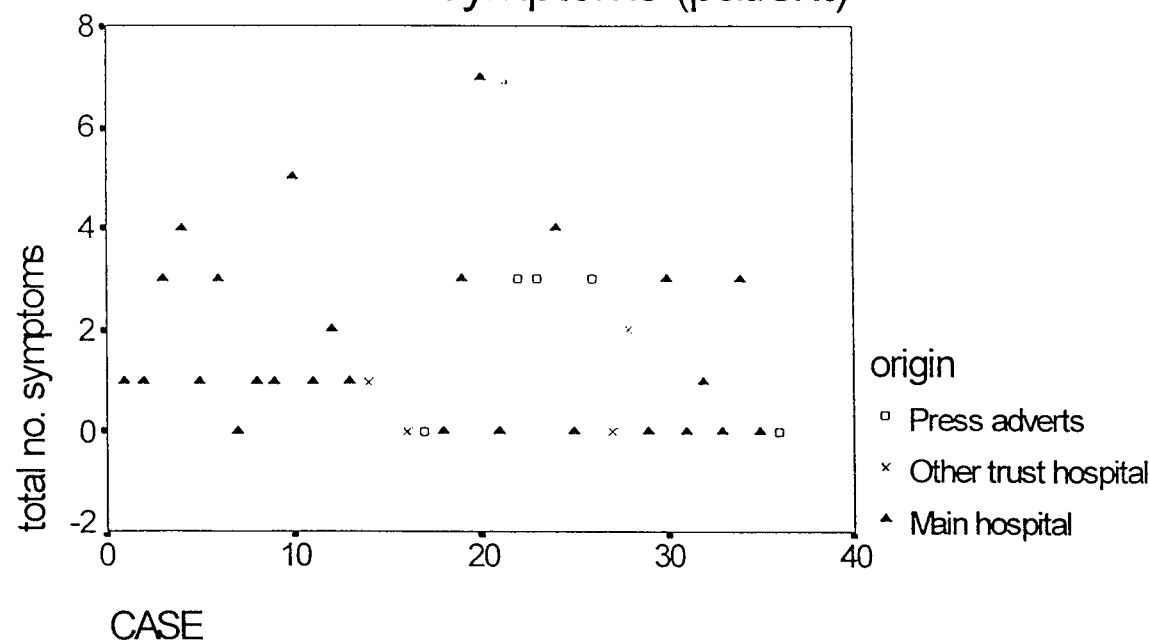
Scatter plot for COPE total (counting method)



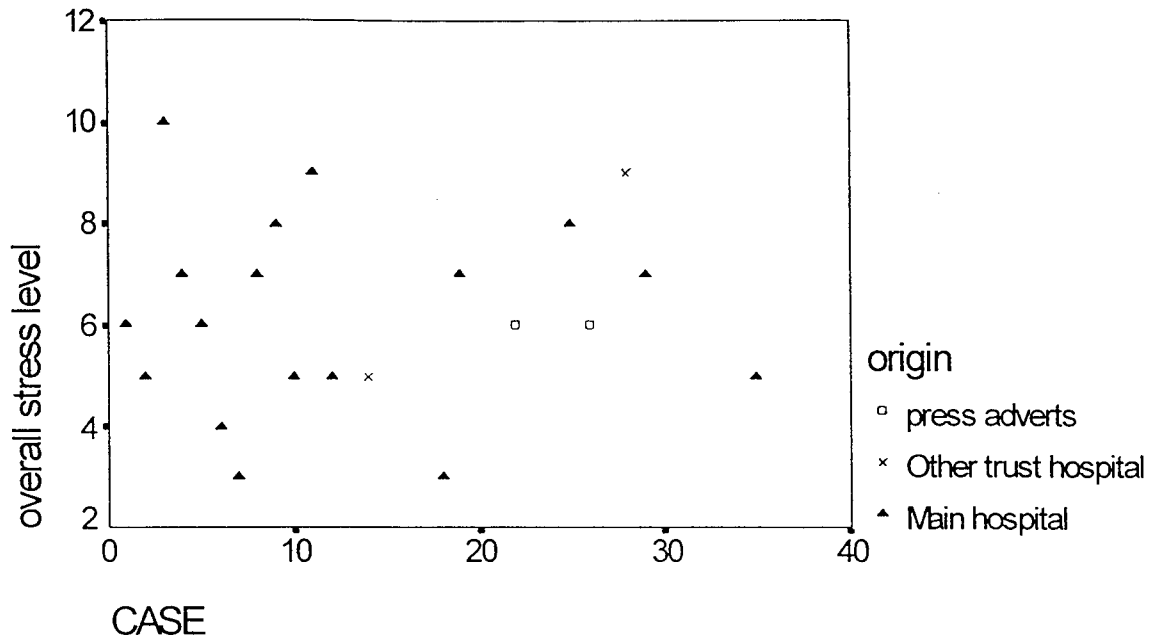
Number of HIV drugs taken by patient



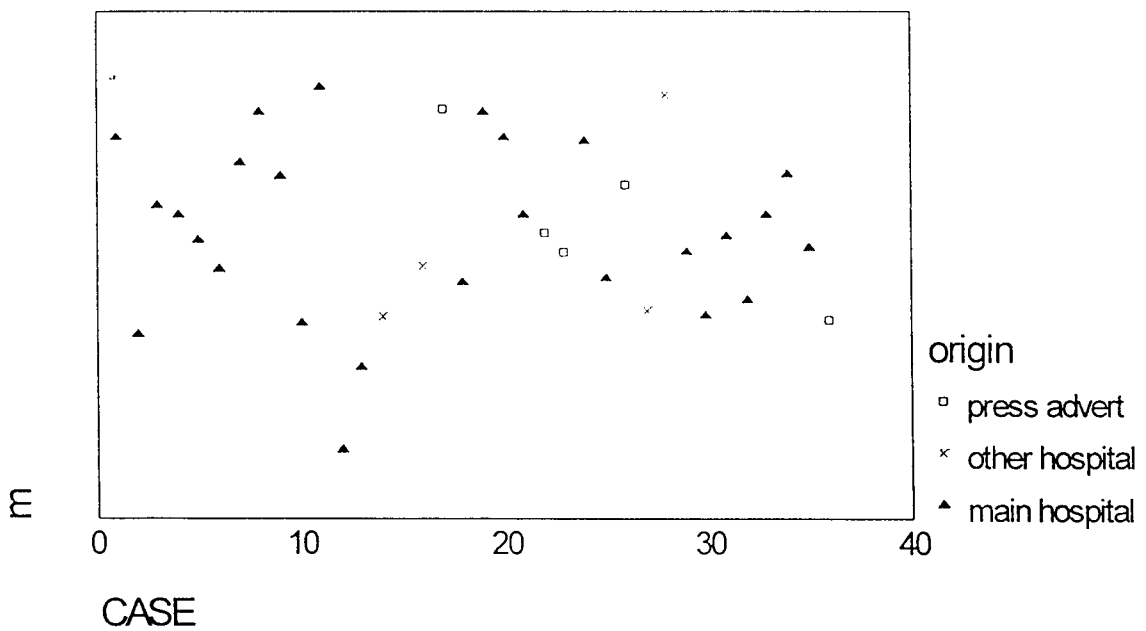
Number of HIV symptoms (patient)



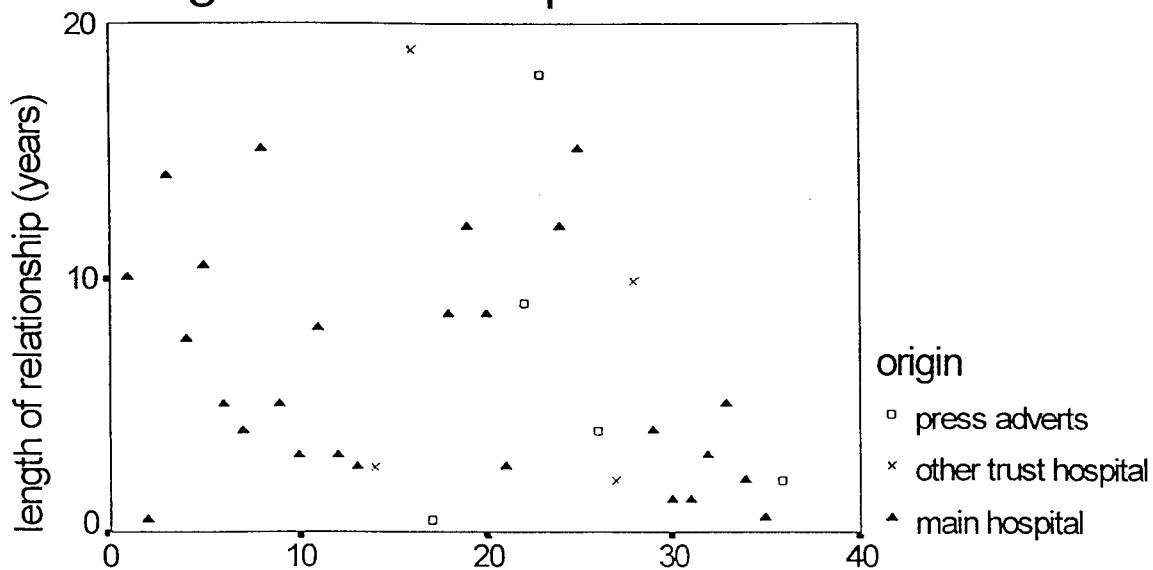
Overall stress level



Mean stress of events

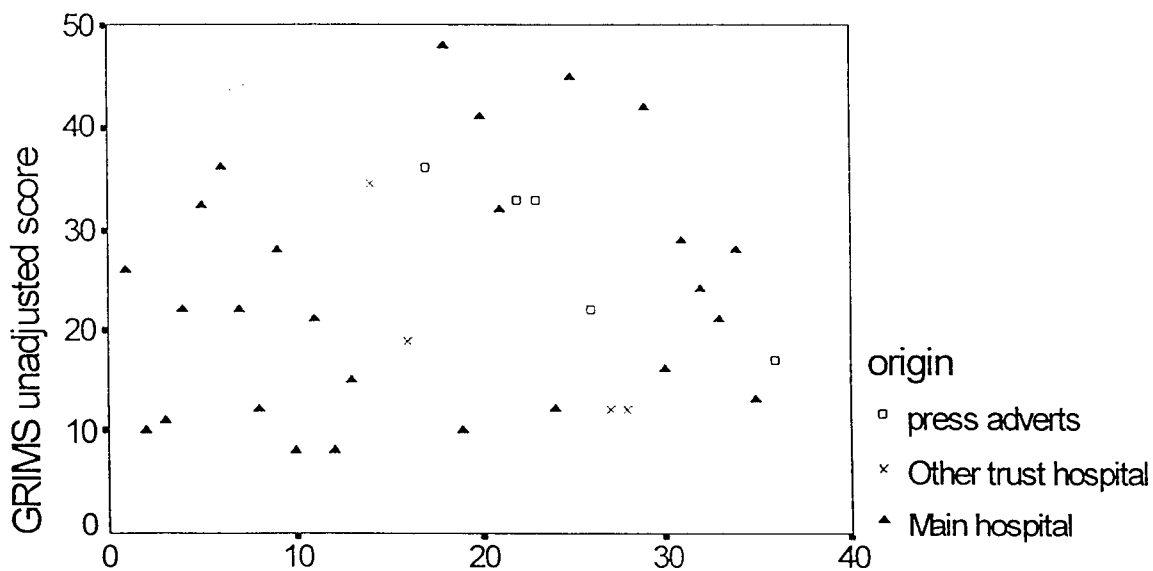


Length of relationship



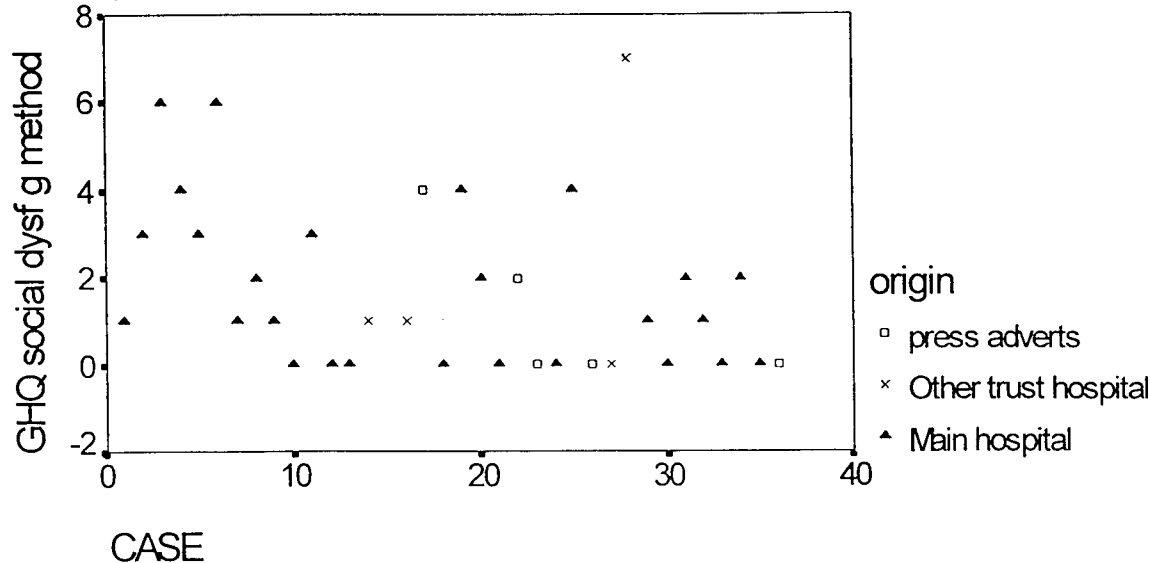
CASE

GRIMS



CASE

GHQ social dysfunction (GHQ scoring method)



GHQ social dysfunction (Likert scoring method)

